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## **The Colored Pill: A History Film Performance Exposing Race Based Medicines**

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*The Colored Pill: A History Film Performance Exposing Race Based Medicines*

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A Dissertation

Presented to

the Faculty of the College of Arts, Humanities and Social Sciences

University of Denver

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In Partial Fulfillment

of the Requirements for the Degree

Doctor of Philosophy

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by

Wanda Lakota

June 2020

Advisor: Dr. Bernadette Marie Calafell

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Author: Wanda Lakota

Title: *The Colored Pill: A History Film Performance Exposing Race Based Medicines*

Advisor: Dr. Bernadette Marie Calafell

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## ABSTRACT

Of the 32 pharmaceuticals approved by the FDA in 2005, one medicine stood out. That medicine, *BiDil*®, was a heart failure medication that set a precedent for being the first approved race based drug for African Americans. Though *BiDil*®, was the first race specific *medicine*, racialized bodies have been used all throughout history to advance medical knowledge. The framework for race, history, and racialized drugs was so multi-tiered; it could not be conceptualized from a single perspective. For this reason, this study examines racialized medicine through performance, history, and discourse analysis.

The focus of this work aimed to inform and build on a new foundation for social inquiry—using a history film performance to elevate knowledge about race based medicines. Equally important, this work adds significantly to the scholarship on filmmaking and argues that film performance can be utilized as both a theoretical and methodological tool.

Written, produced, and directed for this study, *The Colored Pill* history film performance centers on concepts of monstrosity, Othering, and race specific drugs. In addition, the concept of discourse analysis was significant in analyzing the words, phrases, and sentences of eight African American focus groups that screened the 70-minute film performance. Utilizing audio recorded transcripts to analyze the production of knowledge about drugs with race specific indications; data was collected from focus group interviews and questionnaires. Deductive coding, based on William James

McGuire's (1985) model for sequential, information-processing, was used to analyze the data. As a result, pre-established themes of *exposure*, *attention*, *comprehension*, and *acceptance aka yielding* were utilized, because they best pointed to the advancement of knowledge.

The findings underscore the potential of film performance to help overcome knowledge gaps. Focus group participants indicate history film performance, *The Colored Pill*, had a significant effect on the advancement of knowledge on racialized medicines.

*Keywords:* race, medicine, African Americans, qualitative, interview, BiDil, film performance

## **ACKNOWLEDGEMENTS**

The last chapter in this study is called, Giving Up The Ghost. And that, I have done, though I have also kept the faith. Humbly I acknowledge that without God, this study would never have been possible. Thank you, Lord Jesus, for your goodness and mercy that follow me all the days of my life! This research, and subsequent film, has been several years in the making. The work has been long and taxing, but I devoted myself to finishing. Though the typography has been nothing short of mountainous, wrought with many unexpected twists and turns, it has also been rewarding. What a surprise it has been that this opportunity would grow my faith. I never would have made it without holding on to you, Lord.

To Brian, Elijah, and Bianca—thank you! I am so grateful you were there. You guys contributed greatly to my sense of sanity in the un-rosiest of circumstances. To Brian, my beautiful rock, thank you for supporting and cheering me on throughout this entire process. I know you delayed your own personal plans to instead stay by my side during the most difficult part of this process, all while feeding me the most delicious pot roasts and spaghetti dinners known to man. I will never forget your sacrifice. To Elijah and Bianca, you never knew this but your simple encouragements, “You got this, Granny!” came at perfect times when I was feeling low. What a blessing you both are!

Please refer to Appendix H for complete acknowledgements.

## TABLE OF CONTENTS

Chapter One. The Horror of Race Based Medicines .....	1
Introduction.....	1
Contextualizing Race Based Medicines.....	5
Scientific Racism.....	6
Socio-Historical Realities of Race Based Medicines .....	12
Autopsy of BiDil®.....	14
Introducing the Present Study .....	19
Racial Identifications .....	20
Preview of Chapters .....	22
Summary .....	28
 Chapter Two. A Haunted History: Literature Review .....	 30
The History Film: A Historian Perspective .....	30
Challenging the Hegemony of Textualism .....	36
History and History Film .....	42
Film Realism .....	44
Film Re-Enactments .....	45
Impact of History Films on Knowledge.....	47
History Film Performance: A Communication Perspective .....	49
Interplay Between History Film and Film Performance .....	50
Consideration of New Relationships .....	52
History Film Performance: Race Based Medicines .....	53
Gap in Knowledge .....	56
 Chapter Three. Close Encounters: The Seminal Works of Performance Scholars Dwight Conquergood and D. Soyini Madison.....	 58
Methodological and Theoretical Framework.....	60
Performance Ethnography .....	66
Performance .....	71
<i>Imagining</i> Performance as a Strategy to Challenge Textualism.....	74
Performance as an <i>Inquiry</i> into Counter-Narratives .....	77
Performance as an <i>Intervening</i> Strategy for Knowledge .....	80
Summary .....	84
 Chapter Four. Homo Monstrous: The Dark Performance of Horror .....	 86
History as Monstrosity.....	93
Medicine as Monstrosity.....	97
Race Based Medicine as Monstrosity .....	100
Scientific Racism as Monstrosity.....	107
Film as Monstrosity .....	112
Horror Films as Monstrosity .....	114
Human Monster as Monstrosity.....	125
Sound and Music as Monstrosity.....	132
Film Silence as Monstrosity .....	147

Chapter Five. Bone Chilling: <i>The Colored Pill</i> Behind the Scenes.....	150
Contextual Analysis .....	161
Description of Film .....	169
Horror.....	172
Processes .....	175
Finding My Story Through Research .....	179
The Historical Reconstruction .....	182
Writing the Story/Preparing the Shoot.....	183
Visual Storytelling .....	187
The Shooting Day .....	190
The Art of Cinematography, Sound and Music .....	193
Sound Design .....	194
Anatomy of a Scene #1, Opening Sequence .....	199
Anatomy of a Scene #2, The Human Monster.....	201
Anatomy of a Scene #3, The Confrontation of Two Immortals .....	205
Anatomy of a Scene #4, Anarcha Westcott, 1849 .....	210
Anatomy of a Scene #5, Holmesburg Prison Sequence.....	215
Anatomy of a Scene #6, Death Scene Sequence.....	223
Chapter Six. Fright-Fest Focus Groups .....	226
Research Design and Method .....	226
Introduction.....	226
Qualitative Research .....	233
Contextual Frame.....	235
Research Design Work: Reflections from Dr. Dwight Conquergood and Dr. D. Soyini Madison.....	238
Research Design: Design Strategy.....	242
Focus Groups.....	242
What are Focus Groups?.....	243
Focus Group Strengths and Weaknesses .....	244
Content-Oriented Approach to Focus Groups .....	245
Method of Data Collection .....	246
Participant Selection Criteria .....	247
Participant Recruitment .....	249
Protection of Human Participants .....	253
Role of Moderator.....	254
Role of Assistants .....	255
Focus Group Venue .....	256
Testing the Protocol .....	257
Recording the Focus Groups.....	262
Focus Group Interview Protocol.....	263
Method of Data Analysis.....	269
Data Handling .....	271
Thematic Frame .....	273
Data Management .....	277
Data Reduction.....	278



Deductive Coding Analysis .....	278
Applied Coding.....	283
Theme 1. Exposure .....	285
Theme 2. Attention .....	287
Theme 3. Comprehension .....	288
Theme 4. Acceptance.....	290
Reliability and Validity .....	293
Results of Focus Group Questionnaires .....	296
Results of Focus Group Interviews .....	306
Chapter Seven. Giving Up The Ghost .....	310
Summary .....	314
Limitations .....	322
Suggestions for Future Research .....	323
Final Remarks .....	324
References.....	326
Appendices.....	440
Appendix A.....	440
Sample Open Letter of Invitation for Focus Group Participation .....	440
Appendix B .....	442
Informed Consent .....	442
Appendix C .....	448
Demographic Survey .....	448
Appendix D.....	449
Pre-Awareness Survey .....	449
Appendix E .....	451
Focus Group Interview Protocol .....	451
Appendix F.....	461
Post-Awareness Survey .....	461
Appendix G.....	463
Film Screening and Discussion Evaluation Form .....	463
Appendix H.....	464
Complete Acknowledgements.....	464

## LIST OF FIGURES

### Chapter Five

Figure 1. BiDil Pharmaceutical Label .....	152
Figure 2. The Colored Pill Movie Poster .....	154
Figure 3. Filming Tuskegee Monster/Ghosts.....	167
Figure 4. Filming Monster/Ghosts Uprising.....	173
Figure 5. Shooting Interior Scene .....	190
Figure 6. Immortals, Bias and Frank .....	192
Figure 7. Film Location, Boulder, CO .....	207
Figure 8. Application of Special Effects Makeup.....	221

### Chapter Six

Figure 9. Themes .....	276
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## **Chapter One. The Horror of Race Based Medicines**

*“If you are neutral in situations of injustice, you have chosen the side of the oppressor. If an elephant has its foot on the tail of a mouse and you say that you are neutral, the mouse will not appreciate your neutrality”* (Bishop Desmond Tutu, cited in Quigley, 2003, p. 8).

### **Introduction**

When I first became interested in race based medicines, I ran across a story written by South American writer Eduardo Galeano (Galeano, 1992). It is a simple story. Whisker thin. Short as an old man’s dance steps. Yet, it is a powerful story. It is a story that haunted me then. It haunts me now. The story is called, *Christmas Eve*.

Fernando Silva ran the children’s hospital in Managua. On Christmas Eve, he worked late into the night. Firecrackers were exploding and fireworks lit up the sky when Fernando decided it was time to leave. They were expecting him at home to celebrate the holiday.

He took one last look around, checking to see that everything was in order, when he heard cottony footsteps behind him. He turned to find one of the sick children walking after him. In the half light he recognized the lonely, doomed child. Fernando recognized the face already lined with death and those eyes asking for forgiveness, or perhaps permission.

Fernando walked over to him and the boy gave him his hand.

*“Tell someone, ...”* the child whispered. *“Tell someone I’m here.”*  
(Galeano, 1992, p. 72)

*Tell someone I’m here.* I can almost hear his bakery sweet voice. Who wouldn’t feel compassion for that kind of suffering? I can hear the vulnerability in his words, and yet so much is unspoken. The ill body speaks in two voices. One voice is biological. The

other is biographical. One voice speaks to the symptoms that animate the body. The other voice speaks to the stories that animate the life. For me, in the midst of that child's whispered words, a story bloomed that turned me around. That turned my research around. That one soft plea, from a dying child, had me asking myself; how many other stories like his, are out there? How many other dusty, faded stories, from unseen faces, remain untold?

Every face casts a shadow. Currently, we see that shadow in the infantile silhouette as the world's face colors and morphs into something more diverse than we've ever seen. We are facing a type of intercultural metamorphosis, and within that metamorphosis are shadows of individuals huddled two-by-two at the borders and along the shores. The shadows are cast across the bent spines of those who carried the weight of Jim Crow, and in the weathered faces of the migrant worker. Globally and domestically there has been an about-face in our population, with emphasis on the profound changes on our demographic mug. Population statistics are pregnant with the number of individuals of color who dwell within the membranes of this planet. These growing numbers can no longer be denied as insignificant growth patterns, or errors in population densities.

Yet, despite the browning of our globe, human beings remain very much alike. In fact, information from the Human Genome Project (HGP) about our drug responses and weaknesses to certain diseases acknowledge that we humans are all amazingly similar (Lander, Linton, & Birren, 2001; Venter, Adams, & Myers, 2001). Based solely on our DNA, we are more alike than not alike (Barbujani, Ghirrotto, & Tassi, 2013). Despite that, it is our differences that scientists are interested in probing. Those infinitesimal

differences locked inside the human DNA become unfettered visual differences in hair, color of skin, and body shape. They are the kinds of differences that can keep two individuals passing on the train from even looking directly at each other. They are the kinds of differences that caused some to harvest the crop while others eat of it. What is the ticket-taker of that difference? The answer is simple. Race.

Racialized identities have never been more colored than in our current so-called post-racial world. Nowhere are those racialized differences more pronounced than in the cosmos of health. This social inquiry study was prompted by my interest in finding a way to highlight how old agendas in race have come to masquerade as new innovations in health. Qualitative research is often called upon as a strategy of social change (Denzin & Lincoln, 1994). In view of the fact that a goal of my study is to enhance knowledge, this work creates a new space for civic engagement, as it relates to race based medicines. Within this frame, my interest is in film to investigate how racialized identities are drawn into health and specifically, into medicine.

This study began as an examination into race based medicines of the future, but the future was altered because of subsidence of the past. When I first began researching race specific pharmaceuticals, I only had in mind the first race specific drug approved by the Food and Drug Administration (FDA) known as BiDil®. BiDil® is a congestive heart failure pharmaceutical specifically for African Americans

With an investigation of BiDil® in the forefront, I was thorough in my research of race specific drugs. In so doing, I faced forward, not backward. Yet, my research led me to past generations. Following that trail, a single pinprick appeared on the historical map and then, surprisingly, that pinprick was followed by a relentless succession of other

instances of race specific medicines. These things turned my gaze from not just the future, but on the past. I followed the dried breadcrumbs of racialized drugs and drug experiments submerged just below the surface. Within that surface, I found other horrific, low-lying historical accounts. Those accounts pointed to other instances of race based medicine. Some of those instances I already knew about, but many others emerged from the swampland. Toward the horizon, the idea for a historical film emerged. It was one thing to know about the history of race based medicine, but quite another to share that knowledge with others.

In this study, I challenge and manipulate the substantive structures in place which has kept this important health history below the surface. I knew the first step in doing so, would be to raise awareness about the history. In raising a historical awareness, I knew that I would also raise a few monsters. That said, monster theory is not the defining theory for this study. Here, I draw a line between understanding a particular culture while I examine medical fears surrounding that culture. The examination of fear brings me back to an examination of monsters, and in the case of this study, the human monster.

To do so, I was intrigued by the idea of creating a history film performance, but I knew there was a chasm—a complicated relationship—between historians and communication scholars, such as myself. I am also a performance scholar, so to that end, I was fascinated by the opportunity to examine representations of history, race, and medicine in a new film performance. Otañez and Lakota (2015) offer, “Visual stories, especially those that involve wellness and personal change, are widely popular” (p. 119). This visual study provides a model for investigating how history films can provide useful race based medicine knowledge for audience viewers.

The topic of raced based medicines came to me through my work at the University of Denver, which is particularly astonishing in that it was my first unveiling of research in race as a social construct. Inspired by intercultural and film studies scholars, I focused my lens on America's great unfinished argument about race.

*"Tell someone I'm here"* (Galeano, 1992, p. 72). My passion for this topic is compelled by both seeing and experiencing race as a site of pain and suffering. This is particularly troublesome given the fact that the kind of ill health that necessitates medicine, is often also the site of pain and suffering. As a performance scholar, the purpose of this study is to contribute to a body of knowledge regarding a history of racialized medicines, and to offer innovative guidance for film performance scholars.

*"Tell someone, . . ."* the child whispered. *"Tell someone I'm here."* Not long after finding the *Christmas Eve* story (Galeano, 1992), I found another doomed story, this time, of a 17-year old slave girl named Anarcha Westcott. For me, the darkness of her story of racial experimentations retraced the loneliness of the little boy in the hospital who begged for someone to acknowledge him. Somehow, I found that the years between Anarcha's world, the approval of BiDiL®, and my own world, braided themselves together. I wondered, might I have discovered stories, just as Eduardo Galeano once did, torn from the open wounds of medical history? And so, my journey toward a film performance, to be used as a counterhegemonic performance to challenge race based medicines, began.

### **Contextualizing Race Based Medicines**

If it were possible to hire a Cessna to fly 5,000 feet above the United States racialized medicine landscape, what would surely strike me is how much has already

been lost. In this fantastic voyage, where dragons might flap overhead, and stormy waters below intersect with burly men in rubber boots—shrimpers and tug-boats—surely the losses of seeing entire races of people as nothing more than the color of their skin could be viewed. Even from 5,000 feet, the futility of creating medicines based on skin color instead of on health behaviors would not be lost. Yet, this seemingly fantastic voyage is no fantasy. And the voyage is a discovery of history.

From the very genesis of our nation, and throughout the centuries, race, and more specifically the belief in a hierarchy of racial superiority has defined the boundaries of citizenship (Brunsma, Rockquemore, 2002; Glen, 2002; Brodtkin, 1998). Borne from institutions of slavery, displacement, disenfranchisement, immigration and more recently, *post-racial* notions of who we are; racial and ethnic hierarchies have remained life-long fixtures in our national landscape. Biological and social categories endure, due to the fact that we have different, and often flawed, conceptions of race. Unfortunately, these flawed conceptions of race often times open the door for scientific racism.

### **Scientific Racism**

What is scientific racism? Garrod (2006) offers the following explanation, “While science has the reputation of objectively testing theories using the scientific method, scientific racism is the exact opposite. It seeks to create definitions of race and culture based on opinion and extremely questionable evidence” (p. 55). Acton (2006) defines scientific racism “as that view that there are originally distinct, and still clearly bounded categories of human beings, to be called ‘races’ who are genealogically linked and whose distinct physical appearance and/or social characteristics are passed on by biological descent” (p. 1187).



In studies of the history of anthropology, scientific racism has received considerable attention (Brodwin, 2002; Stocking, 1968; 1987; 1996; Trubeta, 2013; Wade, 2004; Zimmerman, 2001). Others have scrutinized the appropriation of scientific racism in classical studies (Challis, 2010; 2013; 2016; Leouissi, 1998). Still others have discussed how race discourses influenced acquisitions and exhibitions of skulls and human remains in museums during the nineteenth and early twentieth centuries (Fabian, 2010; Galanakis & Nowak-Kemp, 2013; Nowak-Kemp & Galanakis, 2012; Redman, 2016).

Historically, science has inaccurately used *pedagogies of scientific objectivity* to assert racist ideologies. Many of those racist sciences and practices included so-called empirically based craniometry studies in the 1700s, or the use of marginalized people as subjects of experiments. This veil of objectivity in science has turned into a useful cloak in which to hide racism. I contend these ideologies allow scientific racism to continue to reinvent itself, while at the same time; it serves as a pretext for marginalizing people.

Scientific racism is thought to have been most common during the *New Imperialism Period* (1880-1914), where it was used in support of European imperialism (Shipman, 1994). In the early 19<sup>th</sup> Century, American physicians participated in the debate on slavery, eagerly providing the “scientific” evidence supporting the biological inferiority that justified and required that Blacks be enslaved (Fofana, 2013, p. 137).

The debate over “scientific” evidence involved very “unscientific” arguments. The premise for many race based experiments rested on a very faulty biological conception of race, where African American bodies often found their way to dissecting tables, operating amphitheaters, classrooms and bedside demonstrations, and

experimental facilities (Blake, 1980; Humphrey, 1973). The irony behind the premise of treating African Americans as though they were lesser than Whites was the notion that information, gleaned from their Black bodies, would also apply to White bodies.

Why would scientists today re-engage in scientific racism by creating a race based drug? While the concept of justifying and legitimizing an existing social order may seem to be something that, in these times, has fallen out of favor, the practice was present in 2005 when the FDA licensed BiDil® solely for the African American population. That drug approval and license began the first step toward once again reifying race, something that has had a long tradition in scientific racism.

Science and medicine have been influential in reifying biological concepts of, and attitudes about, race. As Sally Satel (2002) states, “In practicing medicine, I am not colorblind. I always take note of my patient’s race. So do many of my colleagues” (para. 1). Satel is correct. There was certainly nothing colorblind about the segregated patient wards of the past, or the use of race as a factor in health risk assessments. There is also nothing colorblind about the approval of drug BiDil® based entirely on race (Fofana, 2013).

It is not uncommon for clinicians to routinely note patients’ race in their rounds presentations (Schwartz, 2001). In a recent study, Axt, Hoffman, Oliver, and Trawalter (2016) found that a substantial number of White laypeople and medical students/residents held false beliefs about biological differences between Blacks and Whites. Even in the zeitgeist of our current century, there exists a connection between race and science. Evidence of disparities in pain treatment based on race show that African Americans are undertreated for pain, compared to White Americans (Anderson, Green, & Payne, 2009;

Clintron & Morrison, 2006; Shavers, Bakos, & Sheppard, 2010; Smedley, Stith & Nelson, 2013). Todd et al. (2000) found that African American patients were significantly less likely than White patients to receive pain-relieving drugs for extremity fractures in the emergency room despite similar self-reporting of pain. In a study of nearly one million children diagnosed with appendicitis, Goyal et al. (2015) revealed racial disparities in the pain management of children in emergency departments.

Scientific evidence is critical in a “society obsessed with the sanctity of science” (Guillaumin, 1995, p. 102). Accompanying this level of obsession are significant drawbacks, particularly as they relate to marketing racialized drugs. Norman (1998) speaks on how science has a history of being a marginalizing discourse. After all, inadequate science was behind eugenic beliefs about the inferiority of certain races, a framework for ethnic cleansing in both the Holocaust and slavery.

Washington (2007) shares how, under the guise of science, widely stigmatized concepts of race allowed for an environment where racialized corpses were stolen for unauthorized dissections; Black and Brown bodies (both dead and alive) were propped up for public display; and myriad experimental drugs were forced on test subjects of color. Key to the 40-year Tuskegee Study of Untreated Syphilis in the Negro Male (aka the Tuskegee Syphilis Experiment) was scientific racism with its dangerous premise that untreated syphilis progressed differently in African Americans than it did in Whites (King, 2008). Why? Tuskegee’s ultimate purpose was to *document* the presumption that syphilis was a different disease in Blacks (Jones, 1993). The same scientific racism that sanctioned the deaths of men in the Tuskegee Syphilis Experiment also played a role in 1845, when Dr. J. Marion Sims began race based experiments on enslaved African

American women who endured vesicovaginal fistula (a tear of the opening between the vagina and bladder after childbirth). Scientific racism was present between 1929 and 1974 when the process known as “Mississippi Appendectomy” began sterilizations of women of color without their consent or knowledge. Such cases demonstrate vividly that communities of color (and particularly African Americans) have been medically abused and betrayed by a country that saw them as expendable.

Fast forward to the year 2000 where, in a White House ceremony, results of the HGP were announced. Results illustrate that the concept of race has no genetic or scientific basis (Wailoo, Nelson, & Lee, 2012). Kittles and Benn-Torres (2009) observed that in the United States, “no matter how ‘White’ or ‘Black’ we may appear, strikingly, only 34% of African Americans possess over 90% West African ancestry” (p. 82). Conversely, 98% of European Americans have over 90% European ancestry. This means, self-identified African Americans may in actuality, have quite a diverse genetic makeup.

Bubbling to the surface of the HGP is a revelation of the absurdity of racial hatred. The HGP scientifically proved that regardless of individual race or ethnicity categories, at the level of our DNA sequence, all people are more than 99.9% identical. We are more alike, than unlike. Yet, scientists have scoured every bit of research for evidence on the 0.1% of human genetic difference. This contributes to health taking a divisive turn that erroneously transmutes the 0.1% of biological difference into proving a biological basis for race.

Admittedly, there are genetic distinctions among people in the same race. Sub-Saharan Africa is home to both the tallest (Maasai) and the shortest (pygmies) people. Dark skin is found in all equatorial populations, not just in the *African American race*, as

defined in the United States. If there can be such genetic distinctions among people in the same race, and those differences can contribute to huge distinctions in appearance, imagine how those differences might affect individual health. Here is where turning a blind eye to the concept of grouping people by race, for purposes of scientific studies, morphs into an atmosphere ripe for racialized health.

How prevalent is research regarding race and health? In a review of all articles published in the *American Journal of Epidemiology*, from its inception in 1921 to 1990, Jones et al. (1991) found that an increasing number of studies used race either for descriptive purposes only or as an exclusion criterion. A more recent study of articles published from 1996-1999 revealed a frequent use (77%) of race in methodological design (Comstock et al., 2004). Alarming, the authors found that the majority (57-63%) of articles mentioning race failed to justify its use as a variable or to report the method used to access race (i.e., self-report or pre-existing records). Furthermore, only 30% of articles that included racialized results discussed the findings, and even fewer, 18.7%, made suggestions for further research.

On one end of the spectrum, we have Minow (1990) asking the question, “When does treating people differently emphasize their differences and stigmatize or hinder them on that basis” (p. 51)? On the other end, Crenshaw (1991) states that “Ignoring differences *within* groups frequently contributes to tension *among* groups” (p. 1242). Moving from a focus on *whom* to *what*, the next section covers the social and historical realities surrounding racialized drugs.

## **Socio-Historical Realities of Race Based Medicines**

Often, social construction originates in scholarship tied to epistemology. The term is frequently used to point out individual ways of knowing. To say that an empirical fact like skin color difference is a social construction calls attention to meaning-making. Hacking (1999), however, argues that the primary use of *social construction* is for consciousness-raising. In fact, Hacking (1999) believes that our very world is socially constructed. He believes, as do I, that as we experience an elevation of consciousness, our collective beliefs change. This concept has great bearing on the subject of race specific medicines. Medical scientists construct race and health, as a set of intertwined biological and physical markers. Thus, they view race as a biological construct. On the other hand, social scientists construct race and health, as a set of collective behaviors, shared histories, and binding narratives. Conversely, they view race as a social construct.

Our social construction has a bearing on our consciousness about health and the way individuals see medicine. Many individuals think of medicine in terms of a specific remedy or cure for what ails our physical body. But the type of cure we select drags our social construction into the mix. When individuals think of medicine as a cure for our physical body, we socially construct medicine as a remedy for our body, in other words, for our biology. But, medicine extends itself beyond just our biology. Medical cures are also socially constructed myths, bound by our culture and history. Some cultures socially construct medicine as a healing condition primarily for our spiritual body, as well as our physical body. Those cultures might turn to ginseng, wild black cherry, willow bark and other herbs and plants as medicinal cures for physical and spiritual illnesses. At the same time, other cultures feel much more comfortable with manufactured pharmaceuticals,

therapies, and other remedies as a medical cure. In the case of BiDil®, a cure was medically and socially constructed for what was believed to be the racial component of the ailment (heart failure), rather focusing solely on the physical ailment itself. In this connection, the social construction of race within the scientific community viewed race as the component that dictated or presupposed the illness. Whose consciousness was being raised in the creation of a race based drug? Was the scientific community, in introducing the drug, raising the consciousness of the African American community? Or, did the African American community, in their deep suspicion of the drug, raise the consciousness of the scientific community? From the perspective of the later, the idea of race in heart disease is viewed as something that may *shape* health. For this study, the socio-historical reality of race in race based medicines socially constructs race as a socio-historical influence that *shapes* health, but does not necessarily *dictate* it.

To be clear, I am not attempting to create a new perspective on the socio-historical realities of race based medicines. Instead, I argue that just as race has influenced health, health has been affected by assumptions of race. Throughout the decades, assumptions about race, as a biological construct, have remained. For that reason, creating a new definition for the socio-historical reality of race is beyond the scope of this study. Instead, I offer that boosting the knowledge of racialized medicine addresses our collective history in powerful ways.

The socio-historical reality unfortunately, points to the fact that race based medicines have had a nightmarish past in communities, like mine. Most people know about the grotesque biological experimentations that took place during the Holocaust. Many know of the painful pseudoscientific experiments of the early 1930s, where

members of the Puerto Rican community were deliberately infected with cancer. Yet, the African American community does not know the details of how their community did not escape the injustices of quack medicine.

*“Tell someone I’m here”* (Galeano, 1992, p. 72). Clearly, our global and domestic communities have had a troubled past with race based medicines. The social effects of racialized medicine are not easily seen, but what is at stake in this slippery slope are powerful losses in equity, identity, and health access. All the while, much of the information about race based medicine is tucked neatly beneath not easily discernible medical mumble jumble soaked in alleles, pharmacogenomics/pharmacogenetics, and genetic predispositions. Pharmacogenomics is the study of how your individual genes affect the way pharmaceuticals work within your body. Your genes can predict the way your body will respond to medicines. In order to prevent life-threatening side effects, doctors want to incorporate this information in their assessment of medical treatments. In the case of *BiDil*®, and quite frankly, doctors do not currently have the technology to scan every genetic profile for every African American. That being the case, how do we know that the drug is a pharmacogenomic match to African Americans? To uncover how it is that we came to believe that *BiDil*® would be an efficient match for African Americans, we must take a look at the history of both the drug and heart disease.

### **Autopsy of BiDil®**

Heart disease continues to be the leading cause of death in the US. About 647,000 people die of heart disease in the United States every year—that’s one in every four deaths (Centers for Disease Control and Prevision [CDC], 2020). The risk of dying from heart disease is 1.3 times higher in African Americans compared to U.S. Whites (Mensah



et al., 2015). Additionally, there are other important costs to be considered. The total annual cost for health care and lost productivity due to cardiovascular diseases in the U.S. is \$448 billion dollars (Flack, 2009). The National Heart Lung and Blood Institute (2007) put heart disease at the top, costing \$296 billion in direct health expenditures, \$38 billion in indirect cost of morbidity, and \$114 billion in indirect cost of mortality. Heart failure is an important issue that affects African Americans more than any other group. These gruesome facts serve as the backdrop for creating *BiDil*®, a heart failure drug.

Of the 32 drugs approved by the FDA in 2005, one drug stood out. That drug, *BiDil*®, has the dubious distinction of setting a precedent for the first FDA approved race based medicine for African Americans. From a scientific outlook, *BiDil*® is isosorbide dinitrate and hydralazine hcl. The pharmaceutical is a fixed-dose combination. Mutsatsa and Currid (2013) share that one part of the dose is isosorbide dinitrate, a vasodilator that allows blood to flow more freely through arteries and veins. The other part of the drug combination is hydralazine hydrochloride, which is an arterial vasodilator that prevents muscles from tightening while causing blood vessels to widen. Yet, *BiDil*® is so much more than just an oral tablet.

Unlike other drugs, *BiDil*® has a clearly defined racial indication. What made the approval of *BiDil*® also surprising is the HGP's acknowledgement that based on DNA, all humans are quite similar. With similar DNA, why was the medical community interested in clinical trials to study *differences*, particularly when the approval of the drug biologized race, and added a new wrinkle to scientific racism. When I chronicled the events which lead to the drugs' approval, I discovered that *BiDil*® never started out as a

racial pharmacology. In fact, only after BiDil® traversed through troubled legal and commercial waters, did its racial identity float to the surface.

The 1980s clinical trials of BiDil®, led by Dr. Jay Cohn of the University of Minnesota, other cardiologists, and the U.S. Veterans Administration, found that patients receiving the combination of two drugs appeared to experience a lower mortality rate (Carson, Ziesche, Johnson & Cohn, 1999). At that time, clinical results were presented without mention of race.

In 1989, Dr. Cohn obtained a patent using hydralazine and isosorbide dinitrate, this time licensing the rights to a company called Medco (U.S. Trademark, 1995). Medco developed BiDil® as a *new* single-dose drug (Kahn, 2008). Again, the healing agent was to be used by *all* races. The FDA rejected Medco's drug, not because they did not believe it would work, but because their drug trials did not meet the regulations for a new drug approval (Kahn, 2004). Medco's stock crashed, and the rights to the drug returned to Dr. Cohn (Medco, 1997).

Dr. Cohn re-analyzed old clinical trial data from the early 1980s, this time, looking for a racial aspect. In 1999, a company known as NitroMed bought the rights to BiDil®. With help from public relations professionals, they repositioned the drug as a *new* medication for African Americans. It should be noted there is a commercial incentive to reformulate existing drugs. When drug manufacturers reformulate their products, this also allows them to extend their patents and maintain higher prices.

Still involved in the 2000s, Dr. Cohn and NitroMed filed and received a new patent for BiDil®; only this time they emphasized it as a treatment for African American

patients. Yet, even Dr. Cohn “concedes race is a crude standard for treatment decisions” (Barrett, 2005, p. 24).

Approaching the FDA in 2001 with new patents, NitroMed sought approval and was told they would receive licensing if they conducted a second race specific confirming treatment trial. Raising over \$30 million in venture capital dollars, based on this FDA response, NitroMed initiated what became known as the African-American Heart Failure Trial (Kahn, 2008). The problem with that trial is that it only involved 1,050 self-identified African Americans. Coates (2005) shares, “Critics point out that while the trials showed that BiDil® saved lives, they failed to show whether the drug worked better in blacks than in other groups or that it worked only in blacks” (p. 36).

If *only* African Americans were tested in the clinical trial, how can we be sure the medicine works *better* in African Americans than it would in other races? On the flip side, we cannot begin to quantify the public outcry that would have taken place had BiDil® been approved only for Whites. In short, the makers of BiDil®—a drug whose effectiveness was purported to be based on biological differences—never bothered to actually test those differences. Still, NitroMed found positive results in their drugs’ ability to reduce mortality within the African American population. These results suggested that trial members should be given the drug, but in my view, it simply did not hold up to close scrutiny. Whether African Americans in the clinical trials responded positively to BiDil® simply *because* they are African American seems doubtful. It is much more likely that they responded positively to the drug because those particular sets of trial members were sicker, possibly sicker than White patients tested in prior trials.

At the announcement of NitroMed's findings, their stock tripled (TSC Staff, 2004). Hearing of the race-related health results, the Association of Black Cardiologists (ABC), the National Association for the Advancement of Colored People (NAACP), the International Society on Hypertension in Blacks, and the National Minority Health Month Foundation (NMHMF) lent their support for the drug to the FDA (National Minority Health Month Foundation, 2005). In June 2005, the FDA accepted NitroMed's trial population, made up of *only* African Americans, and approved BiDil®.

To continue clinical developments for BiDil®, NitroMed, Inc. (2001) raised \$31.4 million in private financing. With \$31.4 million raised for BiDil®, do I have to ask why individuals of color, who normally are left at the margins of emerging health progress, were suddenly propelled forward in racial drug development? Might the reasons be stuck to the attractive financial advantage to be gained by the scientific community in using race, not just as a marketing strategy, but also as an indicator of pharmaceutical usage?

By 2006, quarterly reports suggested sluggish sales of the drug (Armstrong, 2008). In 2008, marketing of BiDil® was ceased and NitroMed began to lay off approximately 80% of their staff. By October of that same year, NitroMed announced an agreement with JHP Pharmaceuticals to buy BiDil®. By November, 2008, NitroMed announced a different merger, this time with Archemix Corporation. In the end, both agreements were terminated.

In January, 2009 NitroMed accepted a \$36 million buyout offer from Deerfield Management, calling for that company to own 12% of NitroMed. Today, the drug BiDil® has once again changed ownership, and is now owned by Arbor Pharmaceuticals.

## **Introducing the Present Study**

Few would argue that the vast majority of race based medicine research has been from a scientific perspective. My study centers around a history film performance of race based medicines. Here I am not studying race based remedies in terms of their scientific accuracy, but rather as communication incidents. In fact, this research formulates a new, social strategy of performing racialized health. By utilizing a performative way to narrate not only what takes place in the health world, I also present a new way to illuminate the racialized medicines of the past. This study also helps solve a societal problem by amplifying knowledge of history. In this regard, it strives for accuracy in representing the problem, and tells the audience something worth knowing about our racialized history.

In order to create a new framework for discussing history, race based medicines in general, and the drug BiDil® specifically, we must set a new course to provoke thought and knowledge on the topic. For this reason, the research question (RQ) I pose is:

*How does a history film performance function to affect knowledge of race based medicines?*

A critical reason for addressing this research question derives from the fact that the selected film, *The Colored Pill*, had not been studied from an audience perspective in the past. For this reason, *The Colored Pill* serves as a valuable vehicle to help determine the impact of a history film on knowledge. I have chosen to interrogate this topic using performance-centered pedagogy. In this respect, I have created a visual narrative to advance knowledge.

## Racial Identifications

Racialized medications make a difficult claim in focusing on racial differences, in that it posits there is a *single* culture shared exclusively by African Americans. From a racial identification outlook, this is a difficult position to maintain particularly in the face of inclusion/diversity. It also does not allow for those individuals who identify with multiple races. Kahn (2011) states,

In an increasingly intermixed and complex society, one might ask just ‘how much’ African American one has to be for a race based medication—one half, one quarter, one-eighth? This starts sounding suspiciously like the blood dominated thinking of the Jim Crow era. (pp.130-131)

Hair texture, skin color, and other facial features cannot always be relied upon to accurately fill in the racial gaps. A figure such as former President of the United States Barack Obama is referred to as African American, though his mother was White. Professional golfer Tiger Woods is considered African American, though his mother is from Thailand. Which social categories of race do we place African American Arabs, or Afro Latina/o Americans? Which racial box do we check off when discussing the dark skinned Sheedis in Pakistan and South India? What race is the Makrani in Pakistan? Who are the closest genetic relatives to the Australian Aborigines? Which race do any of us truly *belong* to? While the U.S. Census classifies race, after years of genetic intermingling, does anyone really know how much African American blood they have in their lineage?

In order to support new advances in racialized medicine, should we reinstitute the old *one drop rule* for racial identification, though even that practice was never based on DNA? Additionally, there is the question of how we get the medicine to those people *not*

self-identifying as African American (for varied reasons), but who may benefit from the medicine? Are insurance companies to become guardians of racial identities, preventing anyone who does not fully disclose his/her race from being approved for various medications?

With race specific pharmaceuticals, have we created a pill to heal a race? Drugs are biological. Race is social. Allen (2004) states, “Humans create schemes to classify groups of people based on characteristics such as skin color and perceived ability. These classifications designate social identity categories that we may assume to be natural and permanent” (p. 188). Are race based medicines attempting to use biological classifications to repair a social body? Are these drugs attempting to fix our racial differences with pharmaceuticals? Guillaumin (1999) asks, “Are race based drugs a tool for those who look at the world through a racist lens, but never actually use the word ‘race’ in their lexicon” (p. 43)?

Another question comes to mind, which is, do African American bodies function as *human* bodies? The question seems completely absurd, until one looks closer at the scientific distinctions. Roberts (2011) states, “In the past, the FDA has had no problem generalizing clinical trials involved white people to approve drugs for everyone” (p. 3). Counter that with BiDil®, where the FDA approval had the unfortunate end result of creating a distinction between White and African American bodies. Roberts (2011) argues that the approval of BiDil®, “sent the message that black people cannot represent all of humanity as well as white people can” (p. 3).

Today, most of the medicines on the market have an unmarked racial category, yet are tested on predominantly White populations. Martin, Krizek, Nakayama, and

Bradford (1996) state, “Whites as the privileged group take their identity as the norm or standard by which other groups are measured” (p. 125). True to these beliefs, most medicines on the market are not called “White medicines,” or race based medicines exclusively for Whites. The unmarked racial category in scientific research, which is predominately *White*, becomes a pseudonym for *human*. In short, drugs tested on Whites are applicable for all humans. Nakayama and Krizek (1995) state, “Whether or not one discursively positions oneself as ‘white,’ there is little room for maneuvering out of the power relations imbedded in whiteness” (p. 302). For these reasons, when the FDA approves race specific drugs, like BiDil®, they purposefully or inadvertently send a hate-filled message that African Americans are not as representative of *all* humans as Whites.

Why does this matter? Almost all of us will take some sort of medication over the course of our lifetime. Since we all have genes, genomes, and a racial and ethnic identity, we are all stakeholders in the topic of racialized medicine. That said, it will do us all good to pay attention to this debate as it continues to unfold both nationally and internationally.

With race based drugs, have we torn a page from our historical past where scientists believed African Americans to be physically and genetically distinct from Whites? And how might film be used as a tool to help audiences navigate this terrain critically? This dissertation includes an original feature film, as well as focus group research following a screening of the film, to develop answers.

### **Preview of Chapters**

As this chapter pointed out, despite the browning of the globe, humans are more than 99.9% the same. With that, why is the medical community interested in studying and demonizing *difference*? As a performance scholar, that question was foremost in my



mind, when it came to my interest in pharmaceuticals. The purpose of this study is to contribute to a body of knowledge regarding the labyrinth of history of racialized medicines, to shed light on that history, and to offer innovative guidance for film performance scholars. This work offers a unique contribution to communication by creating a new space for civic engagement as it relates to racially skewed pharmaceuticals. The boundaries of this interdisciplinary study overlap several disciplines—intercultural communication, interpersonal communication, history, film performance studies, and health. Since this study illustrates how race based medicines continue to negatively affect African Americans, it required a critical understanding of race and health.

While a number of academic research studies have sought answers to questions regarding race and health, I expand existing research by applying a different approach—a performance-centered pedagogy. To visually enhance my study of race and health, I wrote, produced, and directed the history film performance, *The Colored Pill*. In this dissertation, I argue for the use of a visual narrative to advance knowledge. I present *The Colored Pill* as a cultural artifact—a tool to challenge and manipulate the substantive structures in place, which have kept racially-coded health history below the surface of knowledge. Creating a new framework for discussing health, history, and race specific medicines, the guiding research question for this study is: How does a history film performance function to affect knowledge of race based medicines?

My primary goal in this study is to elevate knowledge about *BiDiI*®, and other racialized health treatments in our history, by drawing on storytelling as film performance. I argue that film performance can be utilized as both a theoretical and

methodological tool. In this study, I demonstrate the power of storytelling and film performance by utilizing transcript data from focus group interviews to analyze the production of knowledge about race based medicine after viewing the 70-minute film, *The Colored Pill*.

I began this introductory chapter with a story about a young, sick child whispering, “*Tell someone I’m here*” (Galeano, 1992, p. 72). While the fullness of this study points to illness narratives in general, the film associated with the study tells a story about the open wounds of racialized health inequalities. Nowhere is this more visible than from the physical and spiritual wound of BiDil®.

I used the emergence of race in health as an opening to cover the barbaric and ongoing practice of scientific racism. This chapter was organized to reflect how the approval of BiDil® began the first step toward, once again, reifying race—a practice that has had a long tradition in scientific racism, including the fistula experiments of African American women performed by Dr. J. Marion Sims, the sterilizations known as Mississippi Appendectomies, and the Tuskegee Study of Untreated Syphilis in the Negro Male. I described how scientists are actually re-engaging in this same kind of scientific racism as I provided background to the emergence, trials, and disappearance of the race based medicine, BiDil®. One of the great ironies behind the premise of scientific racism is the belief that it is acceptable to treat African Americans as less than Whites, all while also believing that health information gleaned from African American bodies apply to Whites. I concluded this chapter by introducing the dissertation research.

In chapter two, I present a literature review situating this project within the scholarship of history films, particularly films made and analyzed by historians. Chapter

two also examines scholarship on film performance. I argue that this dual focus— history films and film performance—is critical to my study as it blends filmmaking from a historians’ perspective with film performance from a communication perspective. The literature review in chapter two, outlines a gap in knowledge, and provides a critical overview of history in film, and history film performances by exploring the foundation for *doing history*. As Merrill (2006) comments:

History, like performance, is both a *subject* of study and the *object* or fruits of that study. The *doing* of history, inquiring into the past, then, is an act which results in ‘histories’ the narratives or stories or performances which are the objects and products of that study. (p. 65)

Over the years, there has been a growing amount of work done on racialized medicine, but in order to analyze history film performances about race based medicine specifically, in chapter two I review the scholarship. This includes a review of some of the more significant studies conducted in recent years. Chapter two also includes information on film performances centered on historical accounts of race based medicines.

Moving on to chapter three, I provide an overview of performance scholarship in Communication Studies from Dr. D. Soyini Madison and Dr. Dwight Conquergood, whose exemplary work guided this project. Chapter three highlights Conquergood’s approach to performance as epistemology, and D. Soyini Madison’s performance as a methodological and theoretical framework. In this chapter, I articulate how for D. Soyini Madison, performance is not just an approach to inquiry; it is an approach for collaborative meaning-making. I also illustrate how Dwight Conquergood used performance as a tool to communicate with cultures different than his own.

In chapter three, I include comments on film performance both as activism, and as a way of knowing. Energized by D. Soyini Madison's (1998) *performance of possibilities* and Dwight Conquergood's (1982) belief that experience is known through embodied performance, I create an ethic of resistance drawing upon performance as an inquiry into counter-narratives, as well as performance as an intervening strategy for knowledge. These ways of knowing were critical in my creation of the thriller/horror history film, *The Colored Pill*.

Chapter four details *homo monstrous*—the dark performance of horror which points to our habit of naming anything we do not understand as monstrous, while in a paradox, forgetting that the *real* monsters are often human. This is especially true when discussing thriller/horror films like *The Colored Pill*. While on its face, the drug BiDil® was designed to heal, I attribute its approval as a monstrous act that reified race. In chapter four, I point out how the drug is monstrous. The characters in the film, *The Colored Pill*, are monstrous. The music in the film is monstrous. The sounds in the film are monstrous. The time frame and plot surrounding the film are monstrous. With monstrosity so deeply embedded in this study, chapter four also examined horror films as sites of monstrosity.

I consider the relationship of monstrosity to the horror genre, and to performance. I focused on how monstrosity plays out in medicine, race based medicines, and scientific racism. Additionally, I delved into other areas of monstrosity, such as the human monster and film silence. While I did not examine the varied use of sounds in film in general, in this chapter I looked closely at how sound, embodied specifically in horror, serves also as a meaning-making tool. Arguing that sound is an indication of the very presence of the

monster, in chapter four I deepened the conversation by examining sound as a device of fear. Here, I called on *sound as monstrosity*, and even *music as monstrosity*, as the specific acoustemological structures for monstrousness in film. Providing numerous examples from popular films, my *sound and music as monstrosity approaches* pit monstrous sounds against monstrous visuals in horror.

For this study, I enter an arena of debate, calling into question the methodological use of film to represent the past, while at the same time; I present a film performance that offers a new paradigm on pharmacogenomics through the pharmaceutical known BiDil®. With these things as the backdrop, chapter five serves as a behind the scenes look at the filming of *The Colored Pill*. In this chapter, I utilize an unusual filmmaking analysis technique, where I examine the internal workings of many scenes in the film. In chapter five, I call upon a fresh, new way of analyzing films that calls to mind *The New York Times' Anatomy of a Scene*. In doing this, I deconstruct *The Colored Pill*—essentially slowing down to interpret the film in general, and explain pivotal scenes. Of particular concern to this study is the question of whether or not a film performance can affect knowledge about race specific medicines. For this reason, in this chapter I offer filmmaking tips of the trade while at the same time, I detail how I juxtaposed history within the horror genre. I elaborate on the truth of history, as well as the truth of *reenacting* history.

I provide a fuller description and contextual analysis of *The Colored Pill*. I also trace my process for structuring the films' narrative and explain my thought process, methods, and challenges I faced during film production.

Chapter six speaks to the fact that very little research delves into the effectiveness of the monstrous film genre of horror. In this chapter, I uncover horror's ability to not only scare, but to raise consciousness and awareness. I discuss key scholarship from a variety of disciplines, revealing how the mass media is a critical source of consumer information, including communication about scientific studies. Within this chapter, I explain the method of data collection and analysis I utilized to answer this study's research question. To uncover thoughts and revelations of *The Colored Pill* film views about racially skewed drugs and treatments, I explain my process of creating focus group interviews as a tool of data collection. Particularly, I reflect on how scholars Dwight Conquergood and D. Soyini Madison informed my data collection work using performance and filmmaking as a tool for socially constructed knowledge. I also describe data analysis choices, and consider the impact of the thriller/horror film, *The Colored Pill*, as performance history.

My final chapter presents a summary of my findings, the results of my study, as well as future implications. I also address some limitations of my study, and make suggestions for future research. I close out chapter seven by sharing some final remarks about BiDil®.

## **Summary**

This study offers both theoretical and practical contributions by examining race based medicines. From a theoretical perspective, this study also adds to the body of research on history films. Equally important, this study adds significantly to the scholarship on filmmaking by examining a body of work created to accompany this research—a film performance, *The Colored Pill*.

Race has been, and continues to be, a fundamental issue in health. I wish it were not, but we must never forget that health and race have always been intertwined. Yet, I did not want to use race and health as fodder for a popcorn thriller. Truth is, the DNA of America is made up of a long strand of scientific racism. This study is about the history of a particular type of medicine—race specific medicine. This is the part of medicine that has gone relatively unnoticed. It has also been relatively undescribed. Why? Because race is a difficult topic to talk about. Throw in health, and race becomes even a more difficult topic to broach. Yet we must discuss it if for no other reason, it persists as a critically important component of modern and past American history.

As pervasive as medicine has become to our modern life, the history—the full history—remains mostly hidden. Race remains a powerful force in American medicine; it is therefore imperative that we critically examine how we have and continue to use and misuse, race. I situate the development of race based medicines within the politics of race and history, which, I argue, is deeply intersectional and in need of interrogation.

## **Chapter Two. A Haunted History: Literature Review**

### **The History Film: A Historian Perspective**

*“Until lions have their own historians, tales of the hunt shall always glorify the hunter”*  
(African Proverb).

Why should history films matter to a communication scholar? Film performances are powerful communication tools. According to historian Natalie Zemon Davis (1988), “film has countless possibilities for showing more than one story at once and for indicating in a concise and arresting way the existence of other interpretations” (p. 280). History films, that is, interpretive films made by historians, are stories of history, told in concise and arresting ways. This literature review examines scholarship on history films, particularly those films made and analyzed by historians. This review also examines scholarship on film performance. This dual focus is pertinent to my study of a history film performance, as it blends filmmaking from a historians’ perspective with film performance from a communication perspective.

In terms of my positionality, I am an African American filmmaker and a qualitative, performance studies scholar. My current work is braided down the spine of history. I derive from a people, who just two centuries ago, were legally forbidden from acquiring literacy. Call it poetic justice that I should challenge textualism in favor of film performance as a critical means of increasing knowledge of historical events. My work in filmmaking creates a platform where new voices can be heard. The voices I am most



interested in are those of the underserved, socially disadvantaged, and economically oppressed people who stand in the shadows. They are my people, huddled two-by-two at symbolic and literal borders. They are marginalized people, communities of color. This positionality places me well outside the conventional academic track, but I am not alone. Along my research journey, I have met scholars of vision—some historians and some film performance scholars, such as myself. The scholars I have met, albeit from differing disciplines, use film, not just as an approach to inquiry, but as a methodology for meaning-making. Privileging experience, these scholars stand on a platform converging pedagogies of performance, critical engagement and the possibility for change, but they do not huddle together. Though engaged in similar work, film performance scholars in communication and historian filmmakers stand apart from one another. My work in this study creates a bridge for history and film performance scholars to stand side-by-side in our mutual endeavors to create and construct visual representations of history.

In this review of literature, I uncover how historians advocate for social change by using written history and historical films to invoke knowledge. I begin by challenging the closed door of textualism as a long standing and dominant way of knowing. In so doing, I open that door for the possibility of a more inclusive analysis of history filmmaking.

The present study positions film performance as both a theoretical and methodological tool. Scholars such as Della Pollock, D. Soyini Madison, Judith Hamera, Kristin M. Langellier, Bryant Keith Alexander, and E. Patrick Johnson have informed performance studies with a multiplicity of approaches. I have also been inspired by performance scholarship from Erving Goffman, Elizabeth Fine and Roberta Pearson.

Performance scholars, like Holling and Calafell (2011) argue that performance is, “an embodied practice, [which] advances a narrative that is both personal and cultural” (p. 59). As a critical part of narrative research, Langellier (1989) calls performance ideology, a “performative turn [...which] highlights the interdependence of the telling and the experience” (p. 128). Goffman (1959) explored how performance develops in social situations; Fine (1977) looked at performance and discursive practices, and Pearson (1999) examined performance style. Dwight Conquergood (2002b) ventured,

The ongoing challenge of performance studies is to refuse and supersede this deeply entrenched division of labor, apartheid of knowledges, that plays out inside the academy as the difference between thinking and doing, interpreting and making, conceptualizing and creating. (p. 153)

Bauman (1986) defines performance as,

... a mode of communication, a way of speaking, the essence of which resides in the assumption of responsibility to an audience for a display of communicative skill, highlighting the way in which communication is carried out, above and beyond its referential content. (p. 3)

On the other hand, Carlson’s (1996) approach to performance observes that it is, “all human activity...at least all activity carried out with a consciousness of itself” (p.4). On the subject of performance, his views provide a framework for my own. Meaning emerges out of human activity, and thus, we see performance as a way that individuals, within a culture, express themselves. As a pedagogical tool, performance provides a perspective for a connection between not only the subject and the audience, but also between the researcher and the subject.

Acknowledging the growing role of film performance as a narrative form of communication, in my study, I mapped performance onto film performance. Here, I drew

on knowledge from film scholars such as James Naremore (1990) to grasp the relationship between film and performance. In addition, I overlaid the component of history. Merrill (2006) shares, “History, like performance, is both a *subject* of study and the *object* or fruits of that study” (p.65). In film performance, I am both preserving knowledge and preserving history in a format that is a practice and a theory. For me, film performance is critical theory in action. It is a practice-based art that helps me structure the narrative. It is the way I introduce a huge, historical narrative through tiny film details. In film performance, I find the story within the research subject. It is the way that I liberate characters—past and present—within our culture. To that end, some might venture to say that film performance is a communication mirror of our culture. To mirror our culture and reflect the performance of history, I called on archival footage, period costumes, and true lines of dialogue. As a filmmaker, these were my choices to make, and I acknowledge their limitations.

As I struggled to merge the line between the truest depictions of history and film performance, I realized I had a similar struggle with the process of filmmaking as that of historians. Merrill (2006) declares, “Performance historians frequently look for what is missing as well as what is present” (p. 66). I seesawed between creating a powerful film so that particular historical events could be interpreted and analyzed, with choosing film performance to entertain, to educate, and to inform.

For a staggering number of years in America, the prevailing view supports a dependence on the written word for the acquisition of knowledge. While it is true that print based scholarship has an important place at the table, it is also true that millions of

people cannot read. Literary theorist Kenneth Burke (1950) states that print-based scholarship has built-in blind spots. In keeping with the metaphor of blocking out particular fields of vision, are we to believe that those millions of people cannot be a source of knowledge, or does our current dependence on print overlook important barriers to dispensing and receiving knowledge?

As epistemology; film performance is an approach to meaning-making. The same can be said for texts. As a pedagogical tool, film performance provides a unique perspective for connections between not only the subject and the audience, but also between the past and the present. Again, the same can be said for text.

Performance ethnographer Dwight Conquergood (1985) suggests that performance can pull an audience into a sense of the Other, or in dialogue with the Other, in a rhetorically compelling way. Ethnographer D. Soyini Madison (2005) shares that performance brings two “life-worlds [in a way that the] domain of the outsider and the insider are simultaneously demarcated and fused” (p. 194). Both Conquergood and Madison’s work have the kind of activist oriented slant that appealed to me in the making of my research film. Influenced by D. Soyini Madison, in my study, I fuse two life-worlds; one world represented by historical events and the other represented by performance. Providing both the toolbox and the tools for performance work, Dwight Conquergood’s filmmaking focus was on the documentary genre. Dwight Conquergood’s (1990) documentary performance, *The Heart Broken In Half*, focused on Chicago street gangs. In so doing, Conquergood illustrated both his positionality as a filmmaker and as a researcher. By creating a film performance of interviews with gang members,

Conquergood (1990) provided clear evidence of the street life gang members endured. In Conquergood's (1985b) film performance, *Between Two Worlds: Hmong Shaman in America*, he exposed the struggle of Hmong refugees in America. I viewed his documentary (1985b) as a nudge for scholars to use research methods that initiated conversations, rather than remain distant observers. I was inspired by Conquergood, and created research that would allow me to be more than just an observer, just as he was. Conquergood's (1985b) focus on the interview as methodology, particularly as he explained the history of shamanic rituals, was a technique I embraced in the focus group interviews of participants who viewed my film.

The genre for my research film performance, *The Colored Pill*, is a horror/thriller. The history of horror has been examined by numerous scholars (Dixon, 2010; Hutchings, 2004; Kawin, 2012; Rigby, 2011). Hills (2005) looked at the psychoanalytic approach to horror. Hanich (2010) developed a phenomenology of horror, identifying elements of horror in everyday life, while author Robin R. Means Coleman (2011) examined horror as it relates to depictions of African Americans. My racialized hauntings approach to this study looks at film horror through the lens of history.

This research film performance approach to investigating historical events leans toward lessening the gap in scholarship between two disciplines—communication and history. Specifically, this study was accomplished through the union and practice of two distinct yet interrelated disciplinary formations—history and film performance studies.

Though the scholarly roads of history films and research film performance have many similarities, each scholarship approaches their subjects from slightly different

angles and vantage points, illustrated in this review of literature. That said, the relationship between history filmmaking and film performance is uncanny. Both are qualitative. Both are open spaces for public discourse. Both are related to recording. Both are vehicles of knowledge. Finally, both are thought provoking modes of resistance.

The research question posed for this study touches upon four primary areas of scholarship: literature on history films from a historian perspective, the impact of history films on knowledge, history film performance from a communication perspective, and history film performance on race based medicines.

There are several articles and textbooks on written history, and history films as an offshoot of that written history, so I begin my review of literature on that topic by first challenging the hegemony of textualism. I end this scholarship with a review of the research on history film performances on race based medicines.

The immense amount of available literature in history and in film performance prevents a complete review of the literature for each area. Additionally, not all of those sources would be useful to this study. Therefore, I will provide a brief summary of the literature in each topic area that is the most pertinent to my study.

### **Challenging the Hegemony of Textualism**

The craving to understand our histories, those that are personal and those that are collective, seems to be a universal need. One of the core necessities of every generation often centers on the process of telling the past—telling the history. Yet, what is history? Can it be defined? If it can be defined, can it be displayed in film?

We have all heard the term ‘the past informs the present’, but in the 2017 documentary film performance of *I Am Not Your Negro* (Grellety, Peck, & Peck, 2017), author James Baldwin takes on a unique view of the past. In the film, Baldwin states, “History is not the past. It is the present. We carry our history with us. We are our history. If we pretend otherwise, we literally are criminals” (Grellety, Peck & Peck, 2017). While I agree with Baldwin, additional questions regarding history bubble to the surface. Is there a single authority on history? Is written history the most legitimate historical source? If history is not the past, as Baldwin suggests, can it be reborn? Can it be re-enacted? Can it be transformed, and if so, by which medium?

Through a review of the literature, I have discovered that written history books are in search of the truth. Today, few would argue that history books in public schools are used for the dissemination of knowledge. Yet, a century ago, American film director Griffith (1915) famously prophesied that history books would be replaced by movies. He opined that in a not-so-distant future, “the children in the public schools will be taught practically everything by moving pictures.” He said, “Certainly they will never be obliged to read history again” (Griffith, 2015, p. 4). Too bad Griffith was wrong.

Shaped by the conventions of textualism, school children today continue to acquire much of their knowledge from textbooks. The predominant emphasis on textualism certainly does not indicate much growth in our educational systems. That lack of growth can be a detriment to unique ways we might come to understand history, art, and other subjects. After all, historian Hayden White (1966) opines that “when contemporary historians speak of the ‘art’ of history, they seem to have in mind a

conception of art that would admit little more than the nineteenth-century novel as a paradigm” (p. 126).

Not only does valuing of the written word over orality limit a great number of resources we have available to assign meaning, it tends to leave the impression that it, in and of itself, *is* the whole meaning. Relevant to this argument, textualism presupposes that it is not just the text, but that it *is* the history. With this line of reasoning, when it comes to historical records, individual interpretations are not to be trusted.

Calling it *scriptocentric*, scholar Dwight Conquergood (2002) has critiqued the practice of valuing literary history over other ways of knowing. Taylor (2003) urges performance scholars to look beyond traditional written texts. Jameson (1981) cautioned against depending on traditional written texts by arguing that history is *not* a text. Burke (1950) went further when he argued that, “the [written] record is usually but a fragment of the expression” (p. 185).

In the world of analyzing and interpreting signs to be read, there is a disjuncture between social classes of people who have had privileged backgrounds, and those that have endured displacement. Folding this concept into the textualism argument, Dwight Conquergood (2002) offers that only middle-class academics assume that reading and writing are central to everyone’s life. To that end, Conquergood (2002) shares that, “For many people throughout the world ... particularly subaltern groups, texts are often inaccessible, or threatening, charged with the regulatory powers of the state” (p. 147). Here, Conquergood (2002) provides another illustration of the way textualism erroneously appears to be the ultimate trump card in the parsing of knowledge. This



allusion is rooted in a traditional hegemonic power structure, and falls short of grasping the fact there are many areas in our world, and within the non-Western world, where texts are inaccessible. With textualism, forms of knowledge from non-Western areas, and/or the people from those areas, are easily dismissed.

Feminist scholar Patricia Hill Collins (2000) makes note of this epistemological and social tension when she ventures, “Black women engaged in reclaiming and constructing Black women’s knowledges often point to the politics of suppression that affect their projects” (p.3). Unfortunately, knowledge is not the authority. No one can know for you. No one can experience for you. No amount of evidence or experience can convince you if you use your autonomy and thus, your authority, to *not* be convinced. Besides, evidence is only evidence when it has not been camouflaged by suppression. Historicized knowledge based on power of experience, no matter how subversive, should not be diminished. Yet, it is.

When speaking of forms of knowledge from lived experiences, Collins (2000) further replies that, “women are more likely to experience two modes of knowing: one located in the body and the space it occupies and the other passing beyond it” (p.259). Unfortunately, the kind of experiential knowledge that Collins (2000) speaks of, often weakens hegemonic accounts of history and thus, in the subjectivity quagmire, loses its possibility for being acknowledged or believed. Collins (2000) shares, “The methods used to validate knowledge claims must also be acceptable to the group controlling the knowledge validation process” (p. 255). Contested forms of knowledge lose their legitimacy under a blanket of unanswerable questions about the nature and/or

construction of the lived experience itself. Instead, it is said that the facts of history should speak for themselves, which ostensibly means, the facts of the *dominant* history should speak for all, and all other versions should fall silent. The consequences of this *malestream history* make my eyes slowing roll skyward. Scott (1991) states, “Making visible the experience of a different group exposes the existence of repressive mechanisms, but not their inner workings or logics; we know that difference exists, but we don’t understand it as relationally constituted” (p.779).

Unbinding the ostensibly monolithic and orthodox text knowledge, is the subversive way quilts have *made visible* the stories of history. In fact, Dwight Conquergood (1986) shared that “engaged knowledge” (p. 149) was created through quilt making. Quilts contained messages to slaves preparing to flee, and when draped over fences to be aired, were an unnoticeable method of knowledge of map routes. Eichler-Levine (2013) reframes quilts as previously ignored sites of knowledge when she states, “The stories told about quilts provide an oral tradition that contrasts with written narratives” (p.68). Recognizing the imperfection of textualism, performance studies scholar Olga Idriss Davis (1998) speaks about how historical knowledge was enhanced by the cultural and rhetorical artifact of quilt making. To that end, Davis (1998) shares, “The quilt represents, on one hand, the African tradition of folk art and embroidery and, on the other, a political symbol of resistance by Black women to the oppression in America of being both Black and female” (p.68). For these reasons, quilt making was used as a form of knowledge that clearly, does not depend on texts.

Decentering a dependence on text, Christian's (1988) narrative of her bittersweet school days in the West Indies indicates, "I lived among folk for whom language was an absolutely necessary way of validating our experience. I was told that the minds of the world lived only in the small continent of Europe" (p. 72).

I believe what we call knowledge, and those who we herald as being in the fullest possession of it, is at best, only *partial knowledge*. The deeply complicated terrain of full knowledge is rarely accessible. Those who boldly claim to singularly possess full knowledge, probably have the least. Worse, some try, through techniques of denial and suppression, to erase what is known when it fails to saddle up with popular paradigms. In a turn to fantasy, what would vintage quilt makers and publishers of texts say to one another about the acquisition and illustration of knowledge, if they could cross the ocean of their differences? In this surreal setting, could they even fathom each other's triumphs, or would they quibble about individual technique? Even in the modern day, irreconcilable differences between normative history and evidential, non-textual knowledge continue.

I agree with Conquergood's overall implication that we must examine the procedures and processes by which we deem something to be known. Williams (1958) criticizes those who depend on texts when he states, "they fail to notice there are other forms of skilled, intelligent, creative activity such as theatre and active politics" (p. 309). I share Williams' concern for the inflexibility of those dependent on texts, and in their way of seeing anything that is *not* in print as illegitimate. The limitation of this kind of arrogance can forever create a gap in knowledge, at the same time that it eviscerates other ways of knowing.

Some see written history as a construction of narratives. Landsberg (2015) argues, “All written history—even that written by academic historians—is inherently narrative, carefully plotted, fundamentally an imaginative construction on the part of the historian” (p. 11). Further, Jenkins (2003) shares:

Above and beyond, speaking of history and history writing, we should bear in mind that what we call ‘history’ is never *a* history, or even *the* history, of something, that is, a faithful or *the* faithful representation of the past independently of the writing subject, but it is actually ‘histories’ based and dependent upon the very historical context and conjuncture at the time of their production, and, thus, that there is a multiplicity of types of history whose only common feature is that their ostensible object of enquiry is ‘the past’. (p. 4)

The belief that written ‘histories’ is something that has been constructed and produced is supported by historian Robert Rosenstone (2018) when he states, “... ultimately historical events can never be reconstructed as they really were but only constructed as they may have been” (pp. xii-xiii).

It is entirely reasonable to embrace the fact that several interpretive ways of assigning meaning exist. One of those ways of knowing is rooted in film, as we tend to learn quite a bit about history from the film medium. In this next section, I delve further into historical films as they relate to ways of knowing. While textualism has been a dominant way of knowing, a great deal of what students *know* about our historical past comes not from textbooks or teachers, but from Hollywood movies (Briley, 2002; Pultorak, 1992; Wineburg, 2000).

### **History and History Film**

Much of the literature in this area includes discussions on basic assumptions regarding history. Elsaesser (1996) offers, “... the cinema forces us to rethink what we

might (or can) mean by the word, history” (p. 150). American-Canadian historian Natalie Zemon Davis (2000) argues that history is not a closed venture, fixed and still, but open to new discovery. Philosopher Karl Marx (1963) theorized that “men make their own history, but ... they do not make it under conditions chosen by themselves” (p. 15).

I agree with these scholars, as I position history as a living thing that is in a constant state of flux in our social environment. To that end, contemporary media scholar, Bill Nichols (1991) declares that, “history is at once the living trajectory of social events as they occur” (p. 177).

“*Tell someone I’m here*” (Galeano, 1992, p. 72). Rosenstone (2018) uses the term *history film* to refer to film which makes the past meaningful, as opposed to *historical film* which nearly any film could be considered. It is for this reason, that I have also adopted the term *history film* for this study that examines a monstrous, racialized history. Chapman (2009) further teases out the term history film as he shares that it, “is not ‘real’ history, but a constructed version of history that accords with the ideological values of its makers and the cultural tastes of its audiences” (p. 7). As I review the body of literature that focuses on definitions of historical films, a newsreel of categories flutter across the screen covering war movies, westerns, romances, documentaries, and thrillers. Rosenstone (2007) states:

In each of these categories, significant works have been created – films that provide knowledge of, insight into, and interpretation of the lives of individuals; films that let us see, hear, and understand a great deal about not only the person but, in many cases, his or her historical milieu. (p. 15)

While historians tend to broadly define history films as those movies that engage with events of the past, film scholar George F. Custen (1992) adds to the definition of public

history films (biopics), as depictions of “the life of a historical person, past or present” (pp. 5-6 ).

### **Film Realism**

Green (2004) shares it seems entirely plausible that the stories we consider authentic and true to life, are most engaging. An important factor related to a constructed version of history is the level of realism we see reflected in film (Busselle & Bilandzic, 2007; Green, 2004; Hall, 2003; Zhang, Hmielowski, & Busselle, 2007). In support of film’s sense of realism, sociologist Pierre Sorlin (1980) states, “... there is something *real* between a film and viewers that allows them to know that the presentation they are about to see is historical” (pp. 20-21). Furthering the topic of film’s realism, bell hooks (1996) shares, “Movies make magic. They change things. They take the real and make it into something else right before our very eyes ... They give the reimagined, reinvented version of the real ... That’s what makes movies so compelling” (p.1).

Supporting the need for realism in film, renowned Civil War historian James MacPherson (1990) called *Glory* (Fields, 1989), the “most powerful and historically accurate film ever made” (pp. 22-27). *Amistad* (Allen, Spielberg, & Wilson, 1997) has been described as a film that was historically accurate. O’Fault (2016) offers that in films such as *Saving Private Ryan* (Bryce, Gordon, Levinsohn, & Spielberg, 1998), filmmakers were concerned with reinforcing that which was real and authentic.

Brown (1998) offers a contrasting view to film realism saying that historical fictional movies “are artistic and creative interpretations of real events. Such films struggle with ‘the problem of truth’ because ‘meaning lies not in a chain of events

themselves but in the writer's interpretation of what occurred" (p. 1). Davis (1992) cautions, "There are obvious dangers in the "we want realities" approach: falling into naïve empiricism about one's historical material; establishing a new orthodoxy on the basis of one's alleged science; *using history to settle scores*" (p. 160).

### **Film Re-Enactments**

Re-enactments are the way the film illustrates a relationship to the past. Historians have made a distinction between 'real' history in films in the covering of film re-enactments. Responding to this topic, Burgoyne (2007) argues, "In reenacting the past, the historical film employs a variety of techniques to produce a heightened sense of fidelity and verisimilitude, creating a powerfully immersive experience for the spectator" (p. 552). Philosopher Paul Ricoeur (1984) writes, "re-enacting does not consist in reliving but in rethinking, and rethinking already contains the critical moment that forces us to take the detour by way of the historical imagination" (p. 8).

Building on historical imagination, memory scholar Raphael Samuel (1996) describes re-enactments as a "quest for immediacy, the search for a past which is palpably and visibly present" (pp. 175-176). Sorlin (1980) goes even further, stating, "Even if they are based on records, [historical films] have to reconstruct in a purely imaginary way the greater part of what they show" (p. 21).

Both historians and communication scholars are interested in reconstructing the past. Pollock (1998a) shares, "[Performance] ruptures and rattles and revises history; it challenges the easy composure of history under the sign of objectivity. It discomposes history as myth, making of it a scene awaiting intervention by the performing subject" (p.

27). Performance re-creations are a fairly common way to illustrate history, even while the technique calls accuracy into question. Arguably, I tend to believe that performance re-enactments *enhance* history particularly since so much of our history is undocumented. For much of the time, observational footage is not available. Through re-enacted performances the oppression of socially imposed roles is unveiled on stage and examined by both audience and actors simultaneously, thereby enabling a transformative critique of values, attitudes and practices (Alexander 2005; Denzin, 2003). Clearly, in the practice of dramatization, understanding a complicated history is well served through performance re-creations of past events.

Much of the literature defines history films in terms of their relationship to past events. Davis (1988) sees history films as, “those having as their central plot documentable events, such as a person’s life or a war or revolution, and those with a fictional plot but with a historical setting intrinsic to the action” (p. 270). Professor of law, Stubbs (2013), defines historical cinema as films which “engage with history or which in some way construct a relationship to the past . . . [and that] these relationships to the past are created not only by the films themselves but also by cultural contexts in which they operate and the discourses that they generate” (p. 19).

Professor of film studies, Grindon (1994) establishes that history films, “have a meaningful relationship to historical events” (p. 2). Finally, Aaltonen and Kortti (2015) discussed the changes in the relationship between history and documentary film, highlighting the growing acceptance of re-enactment as an expressive tool, with resultant challenges to assumptions about historical authenticity.



## **Impact of History Films on Knowledge**

Recent publications have begun to emphasize history films as a source of knowledge. Mintz and Roberts (2016) report, “Anyone who wishes to know about the United States would do well to go to the movies” (p. xi). While Mintz and Roberts were speaking about the sociological and cultural impact of film, other scholars have studied the educational factors associated with film.

Film as pedagogy is responsible for the acquisition of knowledge. bell hooks (1996) shares, “Whether we like it or not, cinema assumes a pedagogical role in the lives of many people. It may not be the intent of a filmmaker to teach audiences anything, but that does not mean that lessons are not learned” (pp. 2-3). In his work on historical images, O’Connor (1988) notes, “However unfortunate, it appears likely that even well-educated Americans are learning most of their history from film or television” (p. 1201).

The role of film in the acquisition of historical knowledge is undisputed. It is undeniable that history knowledge from film is present when one is asked about the Civil War, or about the dresses worn by women in the antebellum South. Toplin (2002) opines, “For many Americans, and for people around the world, visions of the past emerge from scenes in Hollywood productions” (p. 198). Historian Marnie Hughes-Warrington (2007) argues that for many people, “history is what they see in films and television programs” (p. 1). Rosenzweig and Thelen (1998) provide that in a 1988 study of 1,500 Americans, respondents were, “significantly more likely to encounter history through films and television than through books or museums” (p. 238).

Focusing even further on history film's effect on knowledge, Butler (Butler, Koopman, & Zimbardo, 1995) found that moviegoers interviewed after viewing *JFK* (Ho & Stone, 1991) tended to be more accepting of the conspiratorial explanations of the Kennedy assassination, than those interviewed before watching the film. In a similar design, Koopman et al. (2006) analyzed the impact of *Fahrenheit 9/11* (Moore et al., 2004). Koopman et al. (2006) found that after comparing control group responses of those who answered a questionnaire before viewing the film, with those of the experimental group made up of those interviewed after seeing the film, the experimental group tended to agree with the ideas presented in the film.

Film can represent history in the kind of insightful way that print texts have difficulty achieving. Toplin (2007) shares, "Movies help us to think about the past not in terms of dry statistics but in terms of the flesh and blood characters we have seen *experiencing* history on the screen" (p. 121). Additionally, Francaviglia (2007) states, "... film's power to emotionalize by engaging the viewer offers the potential to tell stories—that is, interpret the historical record—in new and exciting ways like no other medium" (p. viii).

Extensive research was completed on the impact of the film *The Day After* (Meyer, 1983) on audience attitudes (Schofield & Pavelchak, 1985, 1989). Schofield and Pavelchak's (1985, 1989) pre- and post-test measurements showed that film had a huge emotional impact on what viewers believed about their chances of survival in an antinuclear event. Toplin (2007) shares how the film, *Saving Private Ryan* (Bryce, Gordon, Levinsohn, Spielberg, 1998), stimulated public interest in the history of World

War II. The film, *Titanic* (Cameron & Landau, 1997) aroused audience curiosity about the 1912 voyage, and *Schindler's List* (Spielberg, Molen, & Lustig, 1983) made an emotional impact on viewers about the Holocaust. Rosenstone (2018) states, "History on film is largely about emotion, an attempt to make us feel as if we are learning about the past by vicariously living through its moments" (p. 105).

### **History Film Performance: A Communication Perspective**

The dominant way of knowing in the academy is that of empirical observation and critical analysis from a distanced perspective: 'knowing that' and 'knowing about'. This is a view from above the object of inquiry: knowledge that is anchored in paradigm and secured in print. This propositional knowledge is shadowed by another way of knowing that is grounded in active, intimate, hands-on participation and personal connection: 'Knowing how,' and 'knowing who.' This is a view from ground level, in the thick of things. This is knowledge that is anchored in practice and circulated within a performance community, but is ephemeral. (Conquergood, 2002, p. 146)

Theoretically, this research project adds to the development of performance through the critical investigation of a history filmmaking tool. As stated prior, film performances are powerful communication tools. Performance, in and of itself, is a powerful communication tool. Merrill (2006) states, "Performance history . . . like other forms of historicizing, involves the performative act of telling a story—literally calling it into being" (p. 65). Merrill (2006) shares:

Locating oneself as a performance historian implies a positionality, and an acknowledgement of a politics of location. For example, we must recognize how the institutional space of a given archive directs and enables *some* ways of seeing, while obstructing others. (p. 66)

In this film performance study on race based medicines, I call on archival footage, period costumes, and true lines of dialogue to reflect the performance of history. As a filmmaker, these were my choices to make, and I acknowledge their limitations.

Several performance pieces have been published in scholarly journals and books (Allen & Garner, 1995; Becker, McCall, & Morris, 1989; Conquergood, 1988; Jackson, 1998; Jones, 1997; Kemp, 1998; Laughlin, 1995; McCall & Becker, 1990; Paget, 1990; Pollock, 1990; Wellin, 1996). While communication performance scholars have long shown an interest in teaching history through film, the same can be said for historians.

### **Interplay Between History Film and Film Performance**

There has been a very long standing argument between historians and social scientists, particularly in regard to representations of history. In author, James Joyce's (1969) famous book *Ulysses*, there is a remarkable line that points to the contention between the two disciplines, "History ... is a nightmare from which I am trying to awaken" (p. U 3.377). Traditionally, historians have been suspicious of the cinema, articulating "general negative positions on its capacity to accurately render histories" (Guynn, 2006, p.3). Adding to the suspicion, Rosenstone (1995) offers that filmmakers have "problems of weighing evidence, making sense out of random data, explaining the inexplicable, and constructing a meaningful past ... that calls itself history" (p.5).

The complexity in the two viewpoints has resulted in quite a chasm between the opinions of history film scholars and those of communication performance scholars. Historians claim that filmmakers and performance scholars distort history by presenting a sensationalized view. Performance scholars see historians' views as restrictive, and do not adequately take into account contemporary issues. While these two scholars may agree on some of the generic definitions of history films, they hold steadfast to significant disagreements about representations. bell hooks (1996) states, "It has only been in the last

ten years or so that I began to realize that my students learned more about race, sex, and class from movies than from all the theoretical literature I was urging them to read” (p. 3). hooks’ (1996) views are in keeping with Turner (1982) who asserts, “There must be a dialectic between performing and learning. One learns through performing, then performs the understanding so gained” (p. 94).

Bisson (2014) shares, “The dominant perception of historical films centers on the belief that historical films, as mediated narratives, distort history and inject viewers with false history” (p. 1). For performance film scholars like me, nothing could be further from the truth. Waterson (2007) offers the importance of film is in, “multiplying the available points of view on the historical record” (p. 56).

The work of both historians and performance scholars, while full of tensions, have still managed to add to the conversation of historical scholarship. Presidential historian Mark Updegrave (2014) explains the difference between what historian like him do, and what writer-directors like Ava DuVernay do, this way: “While the historian and filmmaker are both, by nature, storytellers, the former builds a narrative based on fact, while the latter often bends truth for the sake of a story’s arc or tempo” (para. 1). Again, as a performance scholar, nothing could be further from the truth.

Given our differences, there are remarkable similarities between historians and performance scholars. Historian E.P. Thompson (1976) states, “the historian has to be listening all the time...The material has got to speak through him” (p. 15). Pollock’s (2006) study of oral history *as* performance takes the same stance when she describes “listening out loud” (p. 88). White (1996) shares, “Many historians are not aware...that

the radical disjunction between art and science, which their self-arrogated roles as mediators between them presupposes, may perhaps be no longer justified” (p. 112).

### **Consideration of New Relationships**

In recent years, a body of work has developed around history films, much of it suggesting the need for consideration of new relationships between cinematic and historical representations. Though years in the making, what is missing in the methodologies between historians and filmmakers is a stronger bridge. That bridge is built on the history film itself. In my view, we need an expansion in methodology where historians see that performance scholars are just as capable as they are, and in fact, have already created many remarkable history films.

Bridging the gap between history and communication scholars is potentially beneficial to both historians and performance scholars. Truth is, historians and filmmakers have both shaped history. Both have been engaged in *doing history*. Lending support to the concept of *doing history*, Merrill (2006) states:

History, like performance, is both a *subject* of study and the *object* or fruits of that study. The *doing* of history, inquiring into the past, then, is an act which results in ‘histories’ the narratives or stories or performances which are the objects and products of that study. (p. 65)

Cufurovic (2018) offers “Ultimately, the representation of history has been shaped and constructed by historian and filmmakers alike over the years” (p. 8). Cufurovic (2018) also wisely offer the following solution:

If historians and filmmakers demand recognition for the way they disseminate historical information they must acknowledge that both shape historical consciousness and are authors of history. While historians tend to disseminate history through scholarly literature, directors disseminate historical narratives through film and storytelling. Both may employ different techniques,

methodologies, approaches and target different audiences. But their role remains the same: they interpret, revise and produce a selective history that aligns with contemporary imagination. (p. 82)

### **History Film Performance: Race Based Medicines**

In order to properly analyze history film performances about race based medicine, I must first provide a brief review of scholarly literature highlighting significant studies, conducted in recent years, on race based medicines. In one example, scholars have conducted research which centered on marketing drugs (Belk, 2011; Bradshaw, McDonagh, Marshall, 2006; Britt & Royal, 2011).

Advances in scholarship that focus on the study of race in pharmacogenomics have been conducted (Alcade & Rothstein, 2002; Cooper, Kaufman, & Ward, 2003; Kahn, 2013, 2012; Sankar & Kahn, 2005; Soo-Jin, 2003, 2005, 2009; Weijer & Miller, 2004).

Researchers have also examined race based medicines and racial health disparities (Chowkwanyun, 2011; Cooper, Yuan, & Rimm, 1997; Epstein & Ayanian, 2001; Harty, Johnson, & Power, 2006; Hebert, Sisk, & Howell, 2008; Morales & Ortega, 2007; Parker & Satkoske, 2012).

A number of investigators have examined race based medicines and medical experimentations (Brandon, Isaac, & LaVesit, 2005; Duster, 2007; Gamble, 1997; Washington, 2006).

In addition, research exists that analyze race based medicines, in terms of racialized difference in drug response (Gillum, Mussolino, & Madans, 1997; Grodon, Street, Sharf, Kelly, & Souchel, 2006; Wood, 2001).

Perhaps, as a result of media related controversy, some research concentrates specifically on the drug, BiDil® (Bibbins-Domingo & Fernandez, 2007; Dorr & Jones, 2008; Ferdinand, 2008; Roberts, 2011; Taylor, Cohn, Worcel, & Franciosa, 2002; Temple & Stockbridge, 2007; Seguin, Hardy, Singer, & Daar, 2008).

My research film was created for a narrowly focused audience. Films which focus on narrow topics for underrepresented groups are small in number. On the other hand, Marcus and Stoddard (2006) share that Hollywood films tend to be made for a broad general audience, “so the history of the majority of this audience, traditionally white and middle class, is emphasized, and dramatic liberty is taken with the story to make it more engaging and understandable for that audience” (p. 28). While I did take some dramatic liberty in the way my research film presents itself, I did not fudge the general truth associated with the topic.

“*Tell someone I’m here*” (Galeano, 1992, p. 72). Influenced by the activist-oriented works of scholars Dwight Conquergood and D. Soyini Madison, I designed my film to be activist-oriented by illuminating a dark chapter in America’s racialized history that would challenge audiences to think more deeply about race and medicine. My study constitutes a starting place from which to shape cultural memory. To that end, Marcus and Stoddard (2006) share:

Films such as *Glory* (1989) and *Malcolm X* (1992), *Snow Falling on Cedars* (1999), and *Dances with Wolves* (1990) depicted stories in U.S. history about African Americans, Japanese Americans, and Native Americans, respectively. These films were told, at least to some degree, from the perspectives of the traditionally marginalized groups being portrayed and provided a more critical perspective than the history often being taught in classrooms. (p. 28)



In my film performance study, I zero in on health issues I believe have historically occupied a privileged place in the field of medicine for too long. My study constitutes a starting place from which to understand the complexity of health, as well as provide a model for investigating how history films are useful in providing race based medical information to viewers. Both scholars of history and scholars of film performance agree that films should be free of racial and gender stereotypes. Yet, while they agree, limited historical representations of race in films exist in the world.

Unfortunately, there are only a few history films that focus on African Americans. Many of these films focus on stories of courage and/or oppression. Films like *Glory* (Fields, 1989), *Malcolm X* (Worth & Lee, 1992), *Mandela: Long Walk to Freedom* (Thompson & Singh, 2013), and *12 Years a Slave* (Pitt et al., 2013), are the few representations that exist. Other films like *The Help* (Columbus, Barnathan, & Green, 2011), *Lee Daniels' The Butler* (Williams, Ziskin, Daniels, Patrick, & Elwes, 2013), *Selma* (Colson, Winfrey, Gardner, & Kleiner, 2014), and *Hidden Figures* (Gigliotti, Chernin, Topping, Williams, & Melfi, 2016), tend to focus on the personal determination of African Americans, in the face of heart-breaking opposition.

As important as all of the above mentioned films are, there are very few history films with a focus on personal, racialized health. One film, *Something the Lord Made* (Sargent, 2004), told the story of surgical techniques. Another film in this vein was *Gifted Hands: The Ben Carson Story* (Angel & Carter, 2009), the story of renowned African American brain surgeon, Dr. Ben Carson.

Though potentially beneficial, there has been limited scholarly research on African American films with an emphasis on race based medicines. To date, there are two of note: *The Immortal Life of Henrietta Lacks* (Ball, Gardini, Macdissi, Pilcher, & Winfrey, 2017), a film about a woman who, in the early 1950s, unwittingly became a pioneer in medical breakthroughs with her human cell line. The second film with an emphasis on race based medicines was *Miss Evers Boys* (Benedetti & Fishburne, 2002). That film was loosely based on African American nurse Eunice Rivers, who was an integral figure in the infamous Tuskegee Syphilis Study (The Tuskegee Experiment) conducted by the United States Public Health Services from the 1930s to the early 1970s.

One of the most notable examples of how race and the presupposition of difference continue to shape American medicine was the approval of the first race based drug known as BiDil®. The purpose of my study is to build on the ongoing research on BiDil® and the ways in which that drug and other race based medicines and treatments intersect in shaping the health of communities of color.

### **Gap in Knowledge**

As revealed, there is a clear gulch between historians and communication film scholarship. History, film performance, and race based medicines are having a three-legged race. Like any other sprint of its kind, success to the finish line depends on speed as much as cooperation. In this particular scurry, the participants are easily seen, but the finish line is not. How can anyone be declared the winner in this tensional environment where the players cannot run together without falling into each other's path? How can

anyone be declared the victor when performance history, a critical solution to invoking knowledge, is rarely seen as a legitimate player?

A number of scholars have utilized film analysis for the study of racialized identities (Harris, 2015; Harris & Mushtaq, 2013; Kinefuchi, 2008; Valdiva, 2004), but these scholars have not focused on race based medicines. Given the targeted audience for the drug BiDil®, I expected to find more film based research on the topic. The current gap in literature regarding films about race based medicine, or even history films based on racialized medicine, is miniscule. The history of race based medicines experimented on African Americans does not belong solely to African Americans. These historical moments belong to everyone, regardless of race or ethnicity, and should be a part of our cultural memory. While this study infuses the conceptual tool of performance to better understand the social implications of race based medicines, few communication studies have explored the topic. This study fills that niche.

### **Chapter Three. Close Encounters: The Seminal Works of Performance Scholars**

#### **Dwight Conquergood and D. Soyini Madison**

*“Who is speaking to whom turns out to be as important for meaning and truth as what is said: in fact what is said turns out to change according to who is speaking and who is listening”* (Alcoff, 1991, p. 12).

Erving Goffman (1959) explored how performance develops in social situations. Illustrating his views on the analysis of communication, Goffman (1986) stated, “I assume that when individuals attend to any current situation, they face the question: ‘What is it that’s going on here?’” (p.8)? I asked myself that question during my research, and also when facing the task of creating a history of research film performance. It is apropos to call on Goffman (1959, 1986) and performance, as his work explored how performance develops in social situations.

There is currently a dearth of performance resources which can assist research film scholars, such as myself, in provoking thought and raising awareness about the social situation of racialized drugs in the United States. Thus, *what is going on here* is an attempt to address this scarcity. *What is going on here* is the creation of a performance research film that is overwhelmingly about medical history—the history of race related medicines and treatments. It is also an examination of the social/cultural history on the same topic.

Creating a film, in and of itself, is no easy feat. The creation of a history research film performance is certainly challenging. Adding to that challenge is the fact that the racialized medicine trail is currently un-blazed. No other history research film performance exists that specifically, and solely addresses the drug BiDil®. There are scant few film features on the topic of racialized medicines, a handful of episodic television shows, but not one history research film performance. Until now.

The overall structure for this interdisciplinary study is multi-faceted. This is a study about pharmaceutical products and medical practices. With that, the very nature of this study extends to medicine in general, and pharmacogenomics, specifically. Pharmacogenomics is the study of how our DNA causes us to react differently to pharmaceuticals. Having been influenced by the film work of Dr. Dwight Conquergood, my overall approach is not solely focused on pharmacogenomics, but also adopts a research film lens. This study draws heavily from Conquergood's inspiring work on research alternatives, as opposed to research that is centered solely in written texts. Drawing heavily from the fervent performance ethnography work of Dr. D. Soyini Madison, this study also adopts a performance studies approach. The intersections of pharmacogenomics, film performance scholarship from Dwight Conquergood, and critical ethnographic work from D. Soyini Madison, have all provided a foundation for this qualitative study of racialized medicine from our past and present histories. This study also examines the undergirding complication of Othering. In this connection, I explore the monstrous Othering of victims of race based medicines.

Finally, this study incorporates focus group interviews as a critical methodology. Doing so, I include a focus group lens into the framework of this study so that I can examine the impact a research film performance has in advancing knowledge about race based medicines. In fact, the research question I pose is: How does a history film performance function to affect knowledge of race based medicines? This study seeks to answer this research question by examining increases in knowledge indicated from focus group interviews about the film, *The Colored Pill*.

For purposes of clarity, the scholarly work selected for this chapter was not chosen as representative of Dwight Conquergood or D. Soyini Madison's immense contributions to published works on performance and ethnography. Rather, the selected writings encouraged and inspired me in the area of performance, as a tool to empower. The actions taken by both Conquergood and Madison offer an ethic of resistance which draws upon the power of marginalized people to overcome and transform negative messages, rather than being confined to the pathologies of despair often created by society. Additionally, their life-promoting writings were selected because they set up a belief system that sees performance as a backbone to both theoretical and methodological work. In this regard, D. Soyini Madison and Dwight Conquergood helped me to crystallize the possibility of creating a performance research film for this study.

### **Methodological and Theoretical Framework**

Pioneer of performance ethnography, Dwight Conquergood (2002) describes the challenge of performance studies this way, "The ongoing challenge of performance studies is to refuse and supersede this deeply entrenched division of labor, apartheid of

knowledge, that plays out inside the academy as the difference between thinking and doing, interpreting and making, conceptualizing and creating” (p. 153).

Rooted in a disparate way to advance both theory and method, while focusing on the heart of performance as praxis, Conquergood de-situates previously defined structures to see components of performance everywhere. Not limiting performance to just that which can be encapsulated in theater, Conquergood (2002) shares:

We can think through performance (1) as a work of *imagination*, as an object of study; (2) as a pragmatics of *inquiry* (both as model and method), as an optic and operation of research; (3) as a tactics of *intervention*, an alternative space of struggle. (p. 152)

Performance, with its multidisciplinary characteristics, crosses several academic disciplines. Conquergood (2000) shared that, “Performance studies is uniquely suited for the challenge of braiding together disparate and stratified ways of knowing” (p.152). To that end, Madison and Hamera (2006) state: “From the established disciplines of history, literature, education, sociology, geography, anthropology, political science, and so forth—the rubric of performance has found its way into discussions and debate as a topic of interest and inquiry” (p. xiii).

If the effectiveness of performance were experienced in color, it would have the tremendous range of being red as Georgia clay, while also being as white as Colorado snow. Performance can be experienced ethnographically in the form of narratives. It can be experienced dialogically and dialectically in discussions and focus groups.

Performance is often experienced in silence in gestures and in artifacts, and yes, performance can also be experienced on the theatrical stage. Given the multiple ways of

knowing in the praxis of performance, Conquergood's inter-disciplinary and multi-disciplinary contributions to performance are long-legged.

Conquergood (1995) shared that in the communication discipline, *praxis* should be "fundamentally about placement, about taking a stand, marking (not masking) the self, positioning one's research ethically, politically, as well as conceptually" (p. 86). His foundational works and thoughts on performance as praxis provided insightful connections for me between the subject and the audience, as well as between the researcher and the subject.

Conquergood's performance as epistemology frame provided me with a clear approach to meaning-making. One of the many ways Conquergood illustrated this frame was in seeing performance as a method to interpret culture (1986, 2002b), in which case, meaning emerged as a way for individuals, within a culture, to both express themselves and to be understood.

Conquergood (1985) nudged scholars like me, to use research methods which initiate conversation, rather than remain distant observers. In fact, his focus on interviewing and initiating conversations as methodology, were techniques I embraced in my film creation, and also in my focus group interviews. Conquergood's work explained how to begin a conversation in communities where the aesthetics of performance are paramount. He saw little difference between performance and culture; observer and observed. He skillfully maneuvered himself in such a way that he could easily examine human realities. In my film work, I mimicked these behaviors by first wading through pharmaceutical data locked away in medical journals. In doing this, I was able to examine



the human realities and the complexities of how pharmaceutical data on race specific drugs reifies race in health. In this research study, I used this pharmaceutical data to start conversations about race based drugs in communities that stand to be the most affected.

Starting these kinds of conversations is important in research. Conquergood (2007) reasoned “one cannot build a friendship without beginning a conversation” (p. 67). His data collection practices often included direct conversations with participants. One of the ways Conquergood (1992b) made visible his data collection practices was when he moved into the Big Red tenement, where he talked, worked, and became familiar with the individuals who lived there. These individuals had been cast aside by traditional Western standards. Similar to Conquergood’s (1992b) Big Red tenement research, the individuals in my film were also cast aside by traditional Western standards.

My work in making visible the victims of racialized experiments and racialized drugs also speaks to individuals who were cast aside by traditional Western standards. Like Conquergood, in my positionality as a filmmaker, I see performance as epistemology. In my film study, this meant I turned to performance to teach audience viewers about the relationships between historically marginalized people, and racialized medicines.

Equipped with a common epistemological view, I see Conquergood’s work in performance as an excellent theoretical and methodological frame for my research. As valuable as I viewed the work of Conquergood, another scholar inspired my study. That scholar is D. Soyini Madison.

D. Soyini Madison is the kind of scholar who uses performance in an exemplary way, not just as an approach to inquiry, but as a methodology for collaborative meaning-making. Madison (1998) communicates,

Creating performances where the intent is largely to invoke interrogation of specific political and social processes means that in our art we are consciously working toward a cultural politics of change that resonates in a progressive and involved citizenship. (p. 281)

Prior to the development of my study, I struggled for a method that would interrogate specific events of history—both past and present—events that have negatively affected communities of color. I knew the method I would choose would be a tool for advancing knowledge of the history events excavated from my research. I found the necessary tools to accomplish my research goals through the work of both Dwight Conquergood and D. Soyini Madison.

In her work, Madison (1998) showcased an intriguing concept —the politics of possibility. She expertly showed this work when she shared a narrative from 1968 cafeteria workers strike against their employer, the University of North Carolina. Later, in 1993, when the University of North Carolina celebrated its bicentennial, some felt it was time to honor the workers’ strike, as well as labor culture on campus. Madison (2003) described it this way, “it was the narratives of [the striking cafeteria workers] ‘identifying themselves as subjects’ and ‘telling their story’ in the mediated space of performance that empowered them before strangers and kin” (p. 475).

In my research, I was emboldened by the way Madison interrogated not only the past social process, but in the way she honored that past by allowing those narratives to come forward. I mimicked this in my study. For my study I wrote, produced and directed

a history research film performance I called, *The Colored Pill*. Many scholars have looked at film performance studies as a topic for theoretical knowledge (Barsam, 1992; Corner, 1996; Guynn, 1990; Nichols, 1991; Nichols, 2001; Ponech, 1999; Renov, 1993; Rosenthal, 1998; Vaughan, 1999; Waldman & Walker 1999; Warren, 1996; Waugh, 1984). Ethnographic filmmakers often turn their lens toward underrepresented people so they might both highlight the rich stories of their lives, while creating a platform for others to become educated on those narratives (Aufderheide, 2007; Coffman, 2009; Rouch, 2003; Saunders, 2007; Ten Brink, 2007). Other scholars (Crawford, 1992; MacDougall, 1998; Minh-ha, 1989; Nichols, 1985, 1994) view ethnographic filmmakers as having a critical role in closing the gap of public awareness.

At the start of my research, I, too, needed a tool for theoretical knowledge. In considering the creation of a film performance to visually display my research, I needed a medium that would support some of the horror that suffuses history. I knew I could receive a tremendous amount of insight into audience viewer knowledge gains by drawing components from both Conquergood and Madison. That said, the only answer for a discourse about race and history was for me to use film as that pedagogical and theoretical tool. By doing this, the film could be used as a counterhegemonic performance that would challenge race based medical inequities by telling an Othered story. In this way, my research would formulate a new social strategy of discussing heart disease/failure, and the extent to which biologically based views about race can threaten communication based views about identity.

The purpose of my research film performance was to bring to light the human experiences surrounding racialized medicines. It was also designed to intensify the knowledge of audience viewers about the drug BiDil®—a heart failure drug marketed specifically for African Americans. In so doing, I position my history research film performance as both a theoretical and methodological tool to advance knowledge about racialized medicines and treatments.

As epistemology; film performance is an approach to meaning-making. Meaning emerges from the performance tool itself. As a pedagogical tool, *The Colored Pill* provides a unique perspective for connections between not only the subject and the audience, but also between the divisions of the past and present.

Both Dwight Conquergood and D. Soyini Madison identified areas of tremendous growth in performance ethnography as a theoretical and methodological tool, however, there exists a considerable gap in knowledge about performance related to history, film performance, and historical events related to race based pharmaceuticals.

### **Performance Ethnography**

In this study, I uncover performance ethnography as a method to guide filmmaking. I uncover how performance can encourage audience participation in social change by using the filmmaking stage as a tool for embodied knowledge. Many filmmakers use performance ethnography to understand and provoke thought about the world through the phenomenology of lived experiences. I am no different. For me, film performance is not just data, as much as it is a tool for discovery, to advance knowledge, and to make changes within our society. In this study I create staged re-enactments of an

ethnographic performance. Like Conquergood, I use performance as a way to interpret culture. Like Madison, this study is a performance of possibilities, which fuses together the performance and the audience.

Both Conquergood and Madison share a similar vision on performance ethnography as a tool. Many scholars have examined film work as the kind of empirical scholarship which instrumentally lends itself to ethnography and mass communication work (Corner, 2008; Nisbet & Aufderheide, 2009; van Dienderen, 2004; Zoellner, 2009). Chris Barker (2010) notes that ethnography, “concentrates on the details of local life while connecting them to wider social processes” (p. 32). D. Soyini Madison (2012) reveals that autoethnography is the study of “one’s own social, ethnic, or cultural group” (p. 197). Within these descriptions of ethnography is my approach to research film performance. In this performance-centered research, I examined the lives of those individuals who have been affected by race specific inequities in medicine and, then connected those individuals to the wider community which tends to be concentrated within communities of color.

Conquergood (2002) called performance ethnography a dialogical performance, while Madison (2005) referred to it as excellent representation. Additionally, Madison (2007) highlighted co-performative witnessing as, “being there and with” (p. 829). Author Arthur W. Frank (1995) unwittingly speaks to *being there and with* when he suggests that the body, as a continual site of discourse, needs to tell what others may not want to hear. I believe it is a type of co-witnessing when an individual tells their illness story—giving the body voice to the presence of illness. What greater co-performative

witnessing is there than the profound dismantling of the dark isolation that accompanies illness? Our very identity is rattled by illness, as the state of being sick is one where we co-performatively witness the duality of being our self, while simultaneously, being very much *not* our self. It has been said that the concept of co-performative witnessing is one that Dwight Conquergood wanted to write about, but died too soon. However, before he passed Conquergood agreed that performance should be free of racial and gender stereotypes. Additionally, both scholars view performance ethnography from a critical lens. I found that Conquergood's (1984) *dialogical ethics* correlates beautifully with Madison's (1999) *performance possibilities* for future work in performance ethnography.

In 1985, when Conquergood was appointed as a consultant to an environmental health program in a Hmong camp called Ban Vinai Refugee Camp, he found performance particularly helpful as a tool for social change. There, he shed critical light on knowledge gaps that exist in traditional Western research. He actively noted how ethnography, as a tool, could create space for the politics of performance and change.

From Conquergood's (1986) work and poetry in *I Am a Shaman: A Life History of Paja Thao, a Hmong Healer*, we experienced glimpses of a world few are privy to. This way of conducting research was invigorating to me and pertinent to my subject matter. Like Conquergood, I shared with my film audience, a part of history that few have been made aware of. In Conquergood's (1985) film, *Between Two Worlds*, the audience viewed life among struggling Hmong refugees. They also experienced the negative toll society has had on their culture, and on their spiritual beliefs. Conquergood's film performance, *Between Two Worlds* (1985), is pertinent to my study, as a part of my

research asks focus group participants to speak on the negative toll racialized medicine has had on the African American culture.

Elaborating on performance studies, Conquergood (2002b) offered, “Performance studies struggles to open the space between analysis and action, and to pull the pin on the binary opposition between theory and practice” (p. 145). Researching the space between theory and practice is an area that was critical to my work. Jones (2006) reiterates Conquergood’s views in Jones’ research which moved from simply studying culture, to inhabiting culture. Easily visible in scholar Bryant Keith Alexander’s (2005) view of performance ethnography is Conquergood’s approach. Alexander (2005) sees performance ethnography as an ethics of open communication with the other.

While performance ethnography has often been researched as a live event, Conquergood’s (1990) film *Heart Broken in Half* serves as an example of how performance embodiment can manifest in a film performance. In fact, Conquergood (1990) used his film *Heart Broken in Half* as a space for dialogic performance, by using the film performance to examine Chicago street gangs.

As with Conquergood, there are several elements of D. Soyini Madison’s work that helped justify my utilizing performance as a frame of my study. I was struck by Madison’s ability to weave together performance-centered pedagogy as praxis. In fact, privileging experience, Madison converges pedagogy of performance with critical engagement, and the possibility for change. Cementing her standing in my work is Madison’s use of performance as a way of amplifying marginalized voices. In doing this, Madison’s work is similar to the work of Conquergood, her mentor and advisor. Both

works galvanized my own. Both Conquergood and Madison agree that performance should be free of racial and gender stereotypes. Though their scholarly roads have many similarities, Dwight Conquergood and D. Soyini Madison each approach performance from slightly different vantage points.

Illustrating the intersections between ethnography and performance, Conquergood looked at the participant observer as a cop performer. Madison (2012) answered with, “Cop performance as dialogical performance means you not only do what subjects do, but you are intellectually and relationally invested in their symbol making practices as you experience with them a range of yearnings and desires” (p. 186). Much of the work I embodied on the set of *The Colored Pill* was the act of co-performance. As both a participant-observer and co-performative witness, who was doing more than directing, I was being *there* and being *with* the actors in what Madison (2007) described as, “feeling, sensing, being, and doing witness” (p. 829). Explaining more on the subject of witnessing, Madison (2009) declares:

I bear witness and in bearing witness I do not have the singular response-ability for what I witness but the responsibility of invoking a response-ability in others to what was seen, heard, learned, felt, and done in the field and through performance. (p. 192)

In the data collection phase of my research, I again called on witnessing in interviews with my focus groups. Truthfully, I find history filmmaking to be a type of witnessing. Supported by Minh-ha (1989), there is an indication that filmmakers from marginalized positions have an imperative to share their own narratives, and create a forum where others within their communities can also share their stories. I felt that responsibility during both the script writing process and certainly through the film direction portion.



Prior to the start of filming, many actors posed questions about both my background and the backgrounds of the individuals they were called upon to portray. This happened so often that I created a space, on set, to bear witness and share truths. Within that space, the actors did not just listen, but had an opportunity to share their own personal stories, while providing thoughts about the lives of those real-life individuals they portrayed. Madison (2009) articulates: “Performance invites us to understand that ‘bearing witness’ is a form of truth. The truth of not what precisely happened here but what profoundly and phenomenologically happened here to me, to us—to an/Other” (p. 195).

In this study, I began the process of bearing witness by exhibiting what happened in history, as well as what is happening within our present culture. In doing this, I argue for the use of film performance for social change. Like many filmmakers, I use performance ethnography to understand and provoke thought about the world through the phenomenology of lived experiences.

### **Performance**

For D. Soyini Madison, performance is not just an approach to inquiry; it is an approach for collaborative meaning-making. Dwight Conquergood used performance as a tool to communicate with cultures different than his own. In fact, one of Conquergood’s (1989, 1992) themes of performance was what he called *kinesis*, which is performance to evoke change. My film on racialized medicines and Conquergood’s (1988) work with the Hmong refugees are examples of kinesis performances as methods to evoke change.

I agree with performance scholars, like Holling and Calafell (2011) who argue that performance is, “an embodied practice,” which “advances a narrative that is both personal and cultural” (p. 59). In this respect, studying performance, particularly for marginalized communities, is critical (Holling & Calafell, 2011). I agree with these views on performance as *The Colored Pill* highlights behaviors of marginalized communities, as well. The telling of the experiences of these marginalized communities is critical to our collective understanding about our histories.

Speaking on the topic of performance ideologies as a part of narrative research, Langellier (1989) calls on a “performative turn [that] highlights the interdependence of the telling and the experience” (p. 128). Conquergood (1989) spoke on the topic of the performative turn, as well as on performance as sites of struggle. In fact, Conquergood (1989) encouraged scholars “to embrace a both/and complexity, instead of an either/or polarization” (p. 84). I consider myself a student of the aesthetics of performance guided by the beliefs of both Conquergood and Madison. Their views on performance as sites of struggle were made visible in my resistance film, *The Colored Pill*.

Clearly, Conquergood saw performance as resistance. Denzin (2018) affirmed Conquergood when he said, “Conquergood uses theatre as a weapon for confronting social injustice” (p. 453). In my study, it was my goal to use my resistive film performance to both advance knowledge, and to serve as a site of social change and advocacy.

D. Soyini Madison and Judith Hamera (2006) state, “Across various academic boundaries, performance is blurring disciplinary distinctions and invoking radically

multidisciplinary approaches” (pp. xii-xiii). Again, for my work, these views supported my own, that performance is activism. Madison (2010) shares her thoughts on performance as an act of activism when she asserts the use of performance, “as a method in the defense of human rights in the actualization of social justice” (p. 26). Madison (2010) shares how performance and activism work together, stating:

Witnessing does not stand from a position of ideological and axiological purity; it contributes to the labor and performances of those researchers and activities who do not simply attempt to reflect the world as a mirror but take up the hammer to build and imagine it differently. (p. 25)

Clearly, Madison (1980) believes that performance is not just a vehicle for telling stories, but sees it as an “everyday act of resistance” (p. 280). Adding to a general overview on activism, Madison’s (1998) *performance of possibilities* is not only a strategy for knowledge, but it “aims to create or contribute to a discursive space where unjust systems and processes are identified and interrogated” (p. 280). Madison (2003) discussed the performance of possibilities as a representation of the practice of performance ethnography. With that, the performance of possibilities has transformative qualities for the performers and the audience.

Madison’s (1998) performance of possibilities ties in with Conquergood’s concept of dialogical ethics. Strikingly, Conquergood called the performance of possibilities level of performance ethnography *a way of knowing*. Similarly, Madison (1998) viewed the performance of possibility “as giving voice to those on the margin” (p. 284). As an alternate process for knowing, Madison (2003) remarks, “the performance of possibilities centers on the principles of transformation and transgression, dialogue and

interrogation, as well as acceptance and imagination to build worlds that are possible” (p. 472).

I was completely energized when I learned that Madison’s (1998) *performance of possibilities* does not accept just being heard and included as its focus, but as its starting point. Drawing on Madison’s work, Winn and Jackson (2011) see the performance of possibilities as a bridge between incarcerated and liberated lives. Researching formerly incarcerated girls, Winn and Jackson (2011) state, “These performances of possibilities rebuke labels such as ‘at risk,’ ‘troubled,’ ‘inmate,’ ‘bad,’ and ‘promiscuous’ and replace them with ‘artist,’ ‘ensemble member,’ ‘responsible,’ ‘thoughtful,’ and ‘literate” (p. 615).

Perry (2016) shared, “Conquergood suggests that performance studies can bring together the divided and fragmented scholarly world. He suggests three *i*’s to organize our thinking about performance: imagination, inquiry, and intervention” (p. 32). Indeed, Conquergood (1988) invites scholars to “imagine, inquire and intervene” (p. 41). Inspired by these three insights, I organize the remainder of this chapter in Conquergood’s (1988) three insights: imagine, inquire, and intervene.

### ***Imagining Performance as a Strategy to Challenge Textualism***

Overwhelmingly, the prevailing view within the United States tends to support a dependence on the written word for the advancement and transfer of knowledge. Conquergood (2002) shares, “For many people throughout the world . . . particularly subaltern groups, texts are often inaccessible, or threatening, charged with the regulatory powers of the state” (p. 147). Drawing upon Dwight Conquergood’s work in textualism, I begin this section by examining practice versus the long standing and dominant

convention of text-centered work for the acquisition of knowledge. Conquergood (2002) observes:

The dominant way of knowing in the academy is that of empirical observation and critical analysis from a distanced perspective: 'knowing that,' and 'knowing about.' This is a view from above the object of inquiry: knowledge that is anchored in paradigm and secured in print. This propositional knowledge is shadowed by another way of knowing that is grounded in active, intimate, hands-on participation and personal connection: 'Knowing how,' and 'knowing who.' This is a view from ground level, in the thick of things. This is knowledge that is anchored in practice and circulated within a performance community, but is ephemeral. (p. 146)

Clearly, an area where Conquergood criticized Western ways of knowledge is the way it privileges the verbal/written word (Conquergood, 2002). Calling it *scriptocentrism* and other times *textocentrism*, Conquergood (2002) critiqued the practice of valuing literary history over other ways of knowing. In his view, *textocentrism* is fraught with privilege given to written forms of knowledge. According to Conquergood (2002), text-centered privilege undermines the vast amount of non-written forms of knowledge in non-western cultures.

Inspired by Conquergood's critique of textualism, Alexander (2005) asked university students to create performances that illustrated group practices, as opposed to those dependent solely on texts. Influenced by Conquergood, other scholars focused on performative writing in their field work (Denzin, 2003; Madison, 2005b), rather than depend solely on text. Burke (1950) argued, "the [written] record is usually but a fragment of the expression" (p. 185), and Taylor (2003) urged performance scholars to look beyond traditional written texts. Jameson (1981) cautioned against the dependence on traditional written texts, arguing that history is *not* a text.

Folded into the strategy to challenge textualism, related to knowledge advancement, is a disjuncture between social classes of people—those who have an upper-class or privileged background versus those who have endured displacement. Highlighting this part of the textualism argument, Conquergood (2002) found that the Garifuna people in Belize tend to use the word *gapencillitin* (translated as people with pencil) to reference those from an upper-class background. Counter that translation with the word *mapencillitin* (translated as people without pencil) to reference people from a working class background. Conquergood (2002) shared, “What is interesting about the Garifuna example is that class stratification, related to differential knowledges, is articulated in terms of access to literacy. The pencil draws the line between haves and have-nots” (p. 314).

Conquergood’s concept of the pencil drawing the line is not only a double entendre, but relates to my research of a social class of people, who were simultaneously, lower class, illiterate, while also being quite wise.

Williams (1958) points out that those who depend on texts, “fail to notice there are other forms of skilled, intelligent, creative activity such as theatre and active politics” (p. 309). I share Williams’ concern for the inflexibility of those dependent on texts, as it tends to see anything that is *not* in print, as illegitimate. The limitation of this kind of arrogant thinking can forever create a gap in knowledge, at the same time that it eviscerates other ways of knowing.

Conquergood (1991) criticized the communication discipline for focusing on language, “particularly those aspects of language that can be spatialized on the page, or

measured and counted, to the exclusion of embodied meanings that are accessible through ethnographic methods” (p. 188). Conquergood (1982) firmly believed that experience is known through the spectrum of embodied performance. Finding agreement for this stance, Bakhtin (1986) stated:

After all, there is no such thing as experience outside of embodiment in signs. It is not experience that organizes expression, but the other way around – expression organizes experience. Expression is what first gives experience its form and specificity of direction. (Bakhtin quoted in Conquergood, 1986, p. 85)

Finally, in Madison’s (1998) discussion of privileging texts by speaking of it as “textual fixation,” she states, “In privileging canonized print productions above oral practice productions, we observe the tendency (in the Arts and Sciences) to prescribe either our meanings or languages upon Others or to simply ignore them” (p. 277). Grounded in notions of Otherness, Madison (1998) goes on to express, “History and politics notwithstanding, written cultures have also colonized orality—epistemologically and ontologically—by way of the production and representation of knowledge” (p. 277).

### **Performance as an *Inquiry* into Counter-Narratives**

Conquergood’s work with marginalized communities implores scholars to think in new ways about the border spaces of disempowered and marginalized people. Nowhere were counter-narratives more apparent than in Conquergood’s work with tenement-dwelling Chicago gangs in Albany Park, as well as the gang members known as the Almighty Latin Kings. In *I Am a Shaman: A Life History of Paja Thao, a Hmong Healer*, Conquergood (1986) explored a counter-narrative poem about conversations he had with the shaman. Additionally, Conquergood used performance and oral histories

before Judges in courtrooms when the rituals of the Hmong immigrants were both, advertently and inadvertently, on trial.

One of Conquergood's (2005) major achievements in counter narratives was his expansion of ethnography in community performance as a means to foster social change. Expounding on that work, Madison (2006b) wrote, "The ethnographic performance not only constitutes an ethics of representation, it not only illuminates field experience, but is an act of data making" (p. 403).

Focusing on counter-narratives, Conquergood (1985) suggests that performance can pull an audience into a sense of the Other in a rhetorically compelling way. In Conquergood's (1985) view, dialogic performance "brings self and other together even while it holds them apart. It is more like a hyphen than a period" (pp. 9-10). As a hyphen joins words together, Conquergood (1985) asked scholars to not just hear the Other, but to be accountable. Challenged by Conquergood's dialogic performance in counter-narratives, Alexander was also struck by the concept of the hyphen. Alexander (2012) shares, "In the hyphen, the productive tensions, the space of the de-centered, the space of dialogic performance, our stories meet and along with the reader, we search for meaning" (p.187).

Brody (1995) was also inspired by Conquergood's concept of dialogic performance. She suggests the hyphen can serve as a site for interpretation. Situating her interest in punctuation with performance studies, Brody (1995) believes that punctuation has the power of discourse. On the performative aspect of the hyphen, Brody (1995) offers, "by performing the mid-point between often conflicting categories, hyphens



occupy ‘impossible’ positions. [...] They make a de-centered position that perpetually presents readers with a neither/nor position” (p. 149).

Conquergood’s concept of pulling an audience into a sense of the Other, is exactly what I aimed for in creating *The Colored Pill*. Madison (1998) cautioned that “our representing most often carries with it political ramifications far beyond the reach of the performance” (p. 283). Heeding Madison’s warning, I respectfully represented the traumatic lived experiences of those long since passed, transforming them from experiences the audience could hardly imagine to embodied experiences the audiences could personally *feel*.

Conquergood (1985) teased out dialogical performance as a way to have a respectful relationship with the Other through performance:

Dialogic performance is a way of having intimate conversation with other people and cultures. Instead of speaking about them, one speaks to and with them. The sensuous immediacy and empathic leap demanded by performance is an occasion for orchestrating two voices, for bringing together two sensibilities. At the same time, the conspicuous artifice of performance is a vivid reminder that each voice has its own integrity. (p. 10)

Bringing counter-narratives into the conversation, Conquergood views performance as that which takes place on and off the stage, bringing people together, as opposed to just forming conclusions. Madison’s (1988) view on using performance as a way of amplifying marginalized voices was beautifully displayed when she shared the performance work honoring the 1968 cafeteria workers strike at Chapel Hill. Seeing performance as a means of resistance, Madison (2002) spoke on the value of dialogical performance as the kind of performance that brings different voices into the dialogue (p. 186).

## Performance as an *Intervening* Strategy for Knowledge

The purpose of this study is to contribute to a body of knowledge regarding our shared history of racialized medicines. This study also presents innovative guidance for research film performance scholars and artists on the telling of a monstrous history and advancing knowledge. The educational component of my research is important to me as I needed to use the film performance as an intervening strategy for knowledge. In those terms, Conquergood (2002) pointed to community performances, songs, and spoken language in oral cultures. Within my own ancestry, music and songs were not only critical to the telling of a cultural history, they *became* history. Conquergood (1986) proclaims that music was not just a “cultural performance” (p. 149). Performance is also functional.

Ripping a page from my own culture, and from part of the history displayed in *The Colored Pill*, is the spiritual “Wade in the Water” (Work, 1901). This spiritual music is clearly a type of cultural performance, for slaves used the song to warn and urge other slaves who either planned to escape, or had already escaped. The functional aspect of the song instructed other slaves to travel along the river, or in the swamp water, to avoid a certain death.

Wade in the water  
Wade in the water, children  
Wade in the water  
God's gonna trouble the water.  
(Work, 1901)

Using music in this functional way, slaves shared critical and embedded messages with their community through song. This song, in particular, illustrates Conquergood’s belief

that music is not just a “cultural performance” (p. 149), but is also functional. The spiritual, “Wade in the Water” (Work, 1901), was used as both a type of resistance, and a way of knowing. Conquergood (1986) points to this type of resistance when he explained, “Forcibly excluded from acquiring literacy, enslaved people nonetheless created a culture of resistance” (p. 150).

Another example of creating the kind of culture of resistance that Conquergood spoke about, is the song “Swing Low, Sweet Chariot” (Willis, 1862). Here is a bit of the lyrics:

Swing low, sweet chariot,  
Comin' for to carry me home  
Swing low, sweet chariot,  
Comin' for to carry me home  
(Willis, 1862)

In the song, “Swing Low, Sweet Chariot” (Willis, 1862), the word *chariot* was code for wagon and/or carriage, used to catch escaped slaves. These kinds of song performances and codes were crucial because during that time, slaves were forbidden from reading or writing. This resulted in slaves not being able to use text centered ways of passing information. Conquergood (1986) shares that while the plantation owner viewed these songs as just music or entertainment; they were in actuality, secret means of accessing and sharing “performed truths” (p. 150).

I believe *performed truths* are not only important parts of the territory of history, but if I woke this morning after journeying through an absurdist subterranean passageway, up over mud-waddling river rats and brushing past runaway slaves; if I

hobbled all the way back to that era of overt scientific racism, knowledge of these kinds of songs would be important parts of the survival of my very soul.

Wisely, Conquergood assessed the need to study varied modes of performances, as critical means of knowing. Conquergood (2002) declared, “The consecutive liminality of performance studies lies in its capacity to bridge segregated and differently valued knowledges, drawing together legitimated as well as subjugated modes of inquiry” (p. 318). Referring to it as *intextuation*, de Certeau (1984) opines, “Every power, including the power of law, is written first of all on the backs of its subjects” (p. 140).

I began this study by sharing a powerful personal narrative from a story called *Christmas Eve* (Galeano, 1992, p. 72). The story speaks of the existence of a patient—a young boy in a children’s hospital, who whispers, “*Tell someone I’m here*” (Galeano, 1992, p. 72). Expanding the topic of personal narratives, D. Soyini Madison (1998) elaborates:

“The subjects themselves benefit from ... the creation of a space that gives evidence that “I am here in the world among you,” but more importantly, “I am in the world under particular conditions that are constructed and thereby open to greater possibility” (p. 173).

“*Tell someone I’m here*” (Galeano, 1992, p. 72).

“*I am here in the world among you*” (Madison, 1998, p. 173).

In the film, *The Colored Pill*, an enslaved girl, Anarcha, lifts herself up from a bloody table and yells, “I’M HERE!” (Lakota, 2017). To Anarcha’s cry, no one shushes her to be quiet, or to be still. In fact, no one answers her at all. With an eye on the communal nature of humans, Bakhtin (1981) notes, “nothing is more frightening than the absence of an answer” (p. 111). Linking to Bakhtin in thought, Myerhoff (1982) asserts,

“unless we exist in the eyes of others we come to doubt our own existence” (p.103).

Supporting that view, Madison (1998) believes that, “human desire implores that we be listened to” (p. 278).

History can be reckoned with in the same implored-to-be-listened-to manner shared by Madison (1998). It is in answer to the beckoning call of history, that I studied the complicated process of helping others to be heard using a research film performance to teach specialized knowledge. Madison (1993) spoke of “specialized knowledge as grounded in praxis of personal narrative performance” (p. 136). Madison (1993) further highlights that, “the teller’s experience is illuminated and made accessible and available as an advocacy discourse for social change and/or affirmation” (p. 215).

Madison (1993) shared the performance of a White student in an African American dominated class. With an emphasis on performance, Madison (1998) wrote, “Performance becomes the means by which we problematize how we categorize who is ‘us’ and who is ‘them,’ and how we see *ourselves* with ‘other’ and different eyes” (p. 282). Critical cultural feminist theorist Maria Lugones (1987) amplified Madison’s beliefs when she wrote, “Only when we have traveled to each other’s ‘worlds’ are we fully subjects to each other” (p. 17).

During the filming of *The Colored Pill*, both I and the actors were allowed a unique opportunity to travel into the worlds of the Other. Through the film performance process, we were able to acquire a fresh perspective on history, albeit a monstrous history. Madison’s (2012) scholarship shares that performance brings two *life-worlds* together such that the “domain of the outsider and insider are simultaneously demarcated

and fused” (p. 194). Influenced by D. Soyini Madison, in my study, I also fused two life-worlds; one, represented by historical events and the other represented by film performance.

### **Summary**

In this chapter, I have illustrated the intersection of the performance work of Dwight Conquergood, and the ethnographic work of D. Soyini Madison. This chapter frames how the theoretical and methodological question surrounding my study has been created by applying the works of both Conquergood and Madison. In this chapter, I also highlighted how the work of these two scholars has been expanded upon by others. By situating the work of Conquergood and Madison in my study, I justified why their approaches are the best approach for me to use in my research study.

In this study, I uncover how a performance research film can intensify knowledge about the relationship between historically invisible people and race based medicines. The structure for my study is multi-faceted. This study is partially centered on BiDil®—the first FDA approved racialized pharmaceutical. In this respect, I call on a field of medicine known as pharmacogenomics. Concurrently, the overall approach to this study has a performance lens. This performance study involves an ethnographic history lens, as well as a framework that supports focus group interviews.

In the next chapter, I examine *homo monstrous*, the dark performance of horror as a part of this research involved the creation of a horror film. For this reason, chapter four demonstrates the relationship between a horror film about history, and the topic of monstrosity.

Monstrosity served as the backstory to research history film performance, *The Colored Pill*. Because the film was created in the horror/thriller genre, chapter four examines horror films as sites of monstrosity. In this connection, chapter four demonstrates the relationships between the horror of racialized health and science, to monstrosities in horror film performance.

#### Chapter Four. Homo Monstrous: The Dark Performance of Horror

“Come now,  
my child  
if we were planning  
to harm you, do you think  
we’d be lurking here,  
beside the path,  
in the very dark-  
est part of the forest?”  
(Patchen, 1968, para.1).

*“There ain’t no grave / Gonna hold this body down” (Ely, 1934).*

*I see dead people.* That was the famously whispered line from the hugely popular film, *The Sixth Sense* (Marshall, Kennedy, & Mendel, 1999). The supernatural horror, centered on 9-year-old Cole, a boy who has an unusual gift—he can see ghosts. The film has a phenomenal premise, but for me, the dramatic twist was not that he sees ghosts, but rather that the ghosts are not the monsters. The real gruesome monsters are not the ones nestled deep in the darkest part of the forest. The real monsters are revealed to be the ones *peering in*—the humans. As the plot goes, not only is Cole aware of his Otherness, he is so terrified of his gift that he will not tell his own mother about it.

*Cole:* I don’t tell her things.  
*Malcolm:* Why not?  
*Cole:* Because she doesn’t look at me like everybody else, and I don’t want her to. I don’t want her to know.  
*Malcolm:* Know what?  
*Cole:* That I’m a freak.  
(Marshall, Kennedy, & Mendel, 1999).



Hold fast your heart, young Cole. You are not a freak. *They* out there, peering into you, are the real monsters. You are not the first to be pushed aside and kicked out because you see the truths of the past. You are not the first Othered to lose his voice to the horror of simply being who you are. By the films' close, it had cleverly sent a message about the importance of acknowledging our communal past, and our connection to that past. I hope I have been able to do the same in my research film, *The Colored Pill*. If we could all do that, we could bring all of the so-called Others—all of the Othered monsters—into the light, and out of the monstrous darkness.

What is it about the dark that makes us shudder? What about darkness triggers our primordial fears? Is it the night crawlers creeping down from trees? Is it the snarling wolf watching the bouncing red riding hood cape? What is it about things that prowl and crawl up from the abyss that frightens us and prickles our spines? These things are the stuff blockbuster horror films are made of. They are also the elements I kept in mind when creating my research film.

The ways in which history has been written and represented is like peering into the darkness of a horror film—the canon of one community, and the curse of another. This alone, is an indication of monstrosity. One individual peers into the darkness and sees the monster, and one individual sees himself being seen. Horrors!

Nietzsche (1973) said, “When you gaze long enough into an abyss the abyss also gazes into you” (p. 84). Coming to the edge of an abyss is already a type of monstrousness if for no other reason than the renunciation of boundaries, but gazing into the nothingness can also be terrifying because that is where we confront ourselves. With

extraordinary prescience, we know that is also the place where monsters lie. But, where did they come from? And, why do they look so familiar?

Like a good thriller, the telling of history has been stuck betwixt and between truth and fiction. Betwixt and between the truth of human history and the fiction of the monster. Keetley (2018) reasons, “The monster, in short, is simply what we call those vast swathes of the human which we fail (yet) to know *as* human” (p. 52). No one can threaten normality like a monster. In that, we could easily describe the liminal realm of monsters and even ghosts monsters as being betwixt and between the natural and the supernatural.

Cohen (1996) shares, “The monster signifies something other than itself: always inhabits the gap between the time of upheaval that created it and the moment into which it is received, to be born again” (p. 4). Adding to that, Wood (2003) ventures that the monster is a representation of society’s repressed fears. In agreement, Calafell (2012) shares, “Monsters are said to reflect the anxieties of their time” (p.112).

At one time, monsters were known as *homo sapiens monstrosus*. We can thank Swedish botanist Carl Linnaeus for that. I wish I had the long end of a poking stick so I could give a good swift jab into the darkest parts of Linnaeus. I wish I could jab him for stirring up anxieties and superstitions about the so-called *homo sapiens monstrosus*—monsters and barbaric abominations lurking in the darkest, scariest parts of the forest.

Stuck in narrow thinking and not understanding sacred traditions passed down by ancestors, Linnaeus saw Othered folk as Goethe (1814-1819) described them as a *troubled guest on the dark earth*. Sounds like how film character, Cole, felt in *The Sixth*

*Sense* (Marshall, Kennedy, & Mendel, 1999). I wish I could ram Linnaeus because, in the midst of the forest of the geographical world, the strange and the odd were forever judged. Losing their dignity must have been quite a blow for those bodies of color and difference. They must have gasped as they heard the societal gavel strike—which was a type of moral monstrosity of its own. With a veneer of normality, western civilization gazed upon the difference of their bodies, and imposed a sentence. These communities of color—the so-called monsters—must have flinched, but in defiance, held their gaze. The verdict? A life-with-no-possibility-of-parole conviction on the crime and construction of being *socially outside*—outside of we, the people, and therefore deemed, monsters.

We, the people, showing no respect to the sacred, pushed aside those whose skin was darker, whose hair was curlier, whose traditions were unfamiliar, and labelled them, irrelevant. We, the people—the wretched people—who would later contaminate the air, poison the streams, incinerate the forests, rape the land, and sully the great salt waters, in the name of civilization, would have the unmitigated audacity to call out another—call out an Other—as monstrous! Why should I be surprised? After all, Calafell (2015) lays out that, “monsters are made, not born” (p.1).

I wish I could make Linnaeus feel the squish of the stick, or box his ears, or at least, wiggle my finger at him (the nice finger) for inflating difference of cultural companions, and for making them *monstrous*. I wish I could do these things to Linnaeus, and so much more, for demolishing what we view as safe, *whom* we view as safe, but even if I could, it would only succeed in making me look monstrous, instead of him.

The words *monster* and *monstrous* (used interchangeably in this chapter) etymologically have the distinction of meaning both *to point to* and *to warn against*. These meanings are critical as they precisely describe what Linnaeus did with victimizing, ostracizing, and stirring up anxieties about the so-called uncivilized monsters that lived and dwelled at the edges of the world. But, this is not a study about the edges of the world. Nor is it a study about the cultural baggage of teratology—strange and odd monstrous living forms. This is a study about humans, many of which happen to be both strange and odd, who are in possession of an invisible mortal soul, and also in possession of genetic variations that are distinctly visible to others. Those genetic variations, human differences in color of skin, texture of hair, etc., come to be seen as racial differences. This study is about the wounds of those differences. The wounds of racism. The wounds of inequalities. Chronic wounds that never quite healed because they were re-opened time and time again, for so many underlying reasons, that they became monstrous. The wound, and the people, became one and they both also became monstrous. And the medicine designed to heal those people—race based medicine—also ulcerated and became monstrous.

Central to my research study was the idea of making the invisible, visible. In this study, I focus on specifically helping a film audience peer into a dark history and see the face of the monster, even if it was their own face. I needed to raise awareness. I needed to expose the monster in an intellectually, honest manner while transmitting deep knowledge through the lens of history.

Because my focus is on a race specific pharmaceutical, this study is also about medicine, and the kind of ill health that necessitates it. It is about medicines dispensed to ill bodies and unfortunately, in the case of many communities of color, it is about medicines dispensed on bodies that are not ill. In the introduction to this study, I shared that the ill body speaks in two voices. One voice is biological. The other is biographical. In the film, *The Colored Pill*, the actual biologically based ill body has passed on. That leaves the biographical body, only there is no one to tell that particular narrative, because few people know those dusty, faded stories. But, every face casts a shadow, and those shadows—the monsters and ghosts—can still rise up to tell their stories even though they are dead.

For the purpose of this study, it is not my intention to name monstrosity as a new method of pedagogy, though it is more than capable of doing so. This chapter on *homo monstrous* exists because monstrosity exists in the world. Because monstrosity exists in the world, it became embedded in my research. The world is full of monsters, and because many of these monsters were uncovered in my research, monstrosity served as the backstory to my research film.

*The Colored Pill* is a thriller/horror. The main character in the film is a monster. Surprisingly, all of the characters are monsters. The music is monstrous. The sounds are monstrous. The time frame and plot are also monstrous. Since monstrosity is so thoroughly entrenched in the film, I thought it only fitting to create a chapter on monstrosity.

Drawing from my film, and many others, this chapter examines horror films as sites of monstrosity. These observations in monstrosity are methodologically crucial to the argument of this study. They demonstrate the relationship of monstrosity to horror, and to performance.

However, what on the surface is a research film is in reality a historical account. The realization that the horrifying depictions in the film are true should be, for the audience, a startling deep moment. The untenable reality that African American humans have been medically experiments on, based on their race, should coexist with African American humans being prescribed a pharmaceutical based entirely on their race. Thus, racialized health is dragged into the present. With an eye fixed on those monstrosities, I tackle a number of subjects pertinent to my research:

- History as Monstrosity
- Medicine as Monstrosity
- Race Based Medicines as Monstrosity
- Scientific Racism as Monstrosity

Driving my study is the research question: How does a historical film performance function to affect knowledge of race based medicines? For that reason, my approach for this study remained solidly in film performance as a pedagogical tool. Key to my filmmaking as praxis approach for this study is the understanding of monstrosity as a way to conjoin racial profiling and thus, race based medicines as sites of injustice. In this respect, relating directly to filmmaking, in this chapter I also tackle:

- Film as Monstrosity

- The Human Monster as Monstrosity
- Sound/Music as Monstrosity
- Film Silence as Monstrosity

### **History as Monstrosity**

With a focus on the monstrous, I wish I could warn Carl Linnaeus and ourselves for that matter that transgressive representations of the Other, tend to backfire.

Historically, when that has happened, the monstrous find a way to their feet, stand up, and with backs against the wall, they strain against constructions of normal. They lace up, ready for a fight, or a revolution, whichever comes first. In the creation of this burning and provocative social Molotov cocktail, the monstrous will burn anything in their path, even if it makes them appear more monstrous. In this respect, I wish I could tell Linnaeus how we, the monstrous Other, edge our way from the dreary repression of being *out there*, to the expression of being *right here*. In concurrence, Cohen (1996) notes:

[Although monsters] can be pushed to the farthest margins of geography and discourse, hidden away at the edges of the world and in the forbidden recesses of our minds ... they always return [asking that we] reevaluate our cultural assumptions about race, gender, sexuality, [and] our perception of difference. (p. 20)

Whether the fear was real or imagined, manifestations of the monsters are in Transylvania, in Atwood's (1985) unlikable educator of handmaids, Aunt Lydia, or if they are in the south side of Chicago, anything feared can be Othered. Did Linnaeus know that his work would unloose fear of Otherness? Did he know of its long-lasting dark undercurrent, where some are seen as the apex of the evolutionary ladder, while others are seen as bestial?

I wish I could freeze-frame Linnaeus' 18<sup>th</sup> century fallacious color-coded taxonomy of humans (*Americanus*, *Asiaticus*, *Africanus*, *Europeanus*), press the eject button on his fears about a monstrous race of *homo sapiens*, and lacerate the snaky tendrils that curled around our thoughts, before they became a lethal virus and a social pandemic. Why? Because right behind our fear of the monster, is our feverish compulsion to maim it, to kill it, kill the spirit, erase the memory, and also to, without guilt, forcibly exorcize every monstrous thing as though they were a strange form of germ warfare.

Sadly, the monstrous stories of history *back then*, crept into the tapestry of modern-day xenophobic and racist mythologies of today. In *The Colored Pill*, the biased main character speaks of accusations he made in history against marginalized communities as he states, "I used the threat of disease to mark Mexicans" (Lakota, 2019). This dialogue from the film is in keeping with Poole's (2011) thoughts, "American monsters ... emerge out of the central anxieties and obsessions that have been part of the United States from colonial times to the present and from the structures and processes where these obsessions found historical expression" (p. 4).

What does all this mean? It means that paranoia and distrust go together like frogs and katydids, but it means so much more than that. Pulitzer Prize winning critic Margo Jefferson (2018) ventures, "Any form of history that gets suppressed, or repressed, or erased out, it comes back to haunt" (M. Jefferson, television interview, October 28, 2018). Jefferson is correct. Going back to the time of the Chinese Exclusion Act, U.S. officials blamed the spread of small pox on the Chinese population, though today, much



of that history has been suppressed. Fears about so-called migrants spreading contagious diseases have been debunked numerous times, but aided by racist campaigns, the concept of the other who brings disease to America repeatedly emerges. What is interesting about U.S. fears is that in countries like Nicaragua, Honduras, Costa Rica, and Mexico, the vaccination rates are higher than the rates in the U.S., particularly for diseases like measles, diphtheria, and polio (Nowrasteh, 2018).

Initially, some might look at incidents in our racialized history, such as those listed above, as specific cases with very little ties to each other. However, when we view racialized history collectively, we see a clear historical framework for the way communities of color have been medically abused and betrayed by the United States by viewing the people as monstrous.

Frankly, incidents like the above, point to the fact that Linnaeus' *homo monstrous* is not as far from the surface as we would like to think it is. Becoming aware of the medical demonizations of communities of color and its social costs, I felt a call to action. For me, thinking that is rooted in *homo monstrous* is the stuff of sci-fi horror films, but in our day-to-day world, we must be careful that our pathological mask of civility isn't slipping. Those past incidents were as real as the recent gathering of white nationalists—walled in monstrous men—succumbing to the vice of racism, who participated in the August 11, 2017 Unite the Right rally in Charlottesville, Virginia with tiki torches in hand. I can still hear their ugly “Jews will not replace us!” rallying cries. The torches of that rally exhibited the kind of fear that holds communities of color in an impenetrable, frozen-in-time inferiority related to savagery, while other racial identities see their lives

in conjunction with the progress of humanity. One is the poison, while the other is the antidote. Isn't that a shining example of Linnaeus' fear of the monster? Truthfully, even if I had a poking stick, or spear, or tiki torch, I have to admit the belief in the boogeyman is not all Linnaeus' doing. While his egocentric views dominated western culture, we did not have to parrot them. We all must take responsibility for the suppression and recreation of history for many years.

This study is an interesting way for me to rediscover history, viewing it through the coteries of those whose morbid obsessions have been for and about races of monsters. Ancient texts relay St. Augustine's belief in dog-headed giants who were descendants of Adam. No weapon could abate the human encroachment to an island in the Indian Ocean where Marco Polo told monstrous lore of *men with heads like dogs and teeth and eyes like dogs*. Also, lest we forget his descriptions of the Otherness of the people of Zanzibar, that Marco Polo described as, "Quite black ... [with] big mouths and noses so flat ... they are horrible to look at" (Strickland, 2003, p. 85). Prior to that, Alexander the Great clouded our view with his wondrous tales of strange races of exotic people, strange in size and skin color, seen during his Indian explorations. Lasting over 2,000 years, Westerners gnawed away at fears gripped by the belief that sub-humans existed—made up of differently-situated races of people. But, what exactly made them monstrous?

In those days, the monstrous included differences in the color of skin, malformed heads, bulbous noses, swollen lips, and hairy legs. Yet even then, in their unfamiliarity, we recognized something that seduced us. Perhaps even then, we had a more literal connection to the Upanishads cry, "Thou art That" (Krishnananda, 1984, p. 6.8.7). Is it

possible that the Other—with their visible irregularities and their great otherness, are uncannily similar to us?

Will we ever resolve the fact that we are inextricably intertwined with the monstrosity of the forbidden, and therefore, linked to the monster? What was then thought of as hideously strange and *monstrous*, would today be viewed as observations of either a species of the Great Ape, human congenital abnormalities, or simply concoctions of the human imagination. *Homo monstrosus* beliefs took place in the nether regions of pre-Enlightenment world, but unfortunately many of those 18<sup>th</sup> century debates that divided humanity and marked differently situated groups of people, went through its eugenics ideologies, and still exists today. Humanity, being so narrowly defined that many have attached a particular race to it, is no longer confined to those who lurk *outside* in the furthest edges of the woods. Instances of monstrosity have found their way to an element of society that is most needed by all. That area is medicine.

### **Medicine as Monstrosity**

What strikes me as curious is the nearly invisible studies today of hauntings related to issues of health. This has not always been the case. From an epistemological point of view, illness and hauntings have been spectral bed fellows for quite some time. Nettleton (2006) shares that one of the more marked improvements in the world of medicine is, “a move from supernatural to natural explanations of phenomena” (p. 3). In fact, it was not until biomedicine added to medicine’s growth, that illness came to be seen as an entity removed from what Foucault (1973) called, the “dimensions of the hidden” (p. 90).

Medicine itself, as a field, has been quite monstrous. Television news is full of instances of illness narratives—trapped souls stuck in an unfeeling, insurance-dominated world where medical hauntings rage. At the top of the laundry list, are severed limbs that are not covered by insurance companies. Also on the list are hidden costs for out-of-coverage items, specialists who are out of network and patients who are out of time. In the midst of decomposing health coverages, it seems everything is reduced, except the deductible. Under the meticulous sutures of health, lay phantom ghostwriters who write for the kind of medical journals that shapeshift science. The monstrousness extends to pharmaceutical companies who hide in the shadows, concealing themselves, their data, and the serious adverse effects of their drugs, tucked neatly and invisibly into the soft marrow of the latest and greatest treatments and cures.

In light of these monstrous behaviors, we cannot forget other unseen elements like the prescribing strategies that glide patients smoothly into addictions, while condemning addiction, all in the name of earning a biopharmaceutical buck. Could it be that the medical market today has become less about healing, and more about what critics call *selling sickness* (Moynihan & Cassels, 2005; Moynihan & Henry, 2006)? We cannot be too surprised. After all, what really drove BiDil®, the first race specific pharmaceutical for African Americans, was the race to achieve commercial advantage.

Few draw connections between the madness of the greed-driven, capitalist pharmaceutical industry and its monstrousness, but if we lean in, we will discover that the commodity-machine that must be contained, at all costs, forever bares its teeth in the background of health. Like a good monster, the medicine is there, but only if you have

the right insurance coverage. *Ask your doctor*, they tell us on the health advertisements, only don't because your doctor has only a few short minutes to get to your major complaint. Few draw connections between the extreme horror and mental anguish of those whose fragile lives are ruled by the greed of medicine. We hardly look at the expense of keeping the pharmaceutical commodity-machine going, because we have to keep it going. We have to keep the machine going because we want to stay alive, and they have the tonic water. Only a monstrous species would feed off pain, and yet we hold that industry in the highest of esteem. All of these things are the monstrous sides of medicine, and all of these things point to a pharmaceutical market calibrated in unhealthy people. When you add in all the under-reported deaths in medicine, it's enough to make a ghost say, *booo*.

My research on BiDil® confronts several shared manifestations of both hauntings and illnesses. Gordon (1997) notes, and I concur, "To study social life one must confront the ghostly aspects of it" (p. 7). Some of the ghostly aspects of the social life of race based drugs reach into the outer limits of experiments conducted on human guinea pigs and laboratory rats. They cut across the binaries of sickness and health. They cross the borders between monstrousness and normality. Interestingly, the practices of crossing boundaries, cutting binaries, and glimpsing into the outer limits are the same qualities that ghosts embody. Make no mistake; my research into this dismal area was hardly a magic carpet ride. My research books were dog-eared. My back was bent. My eyes, crossed. My myths, shattered. Researching racialized medicine was torturous. Along the way, I was introduced to monsters and ghosts, victims of race based medicines and

experiments. In acknowledging and reckoning with monster/ghosts soaked and saturated in past injustices, I transformed my research into film—into a type of hybrid film that was a fiction based on true life and death events. French biologist and film innovator Jean Painlevé (2000) noted, “It never would have occurred to the pioneers of cinema to dissociate research *on* film from research *by means* of film” (p.162). At the time, Painlevé (2000) was specifically referring to 21<sup>st</sup> century biologists’ film depictions of bacteria and cells; however his thoughts are well taken. In this study, I was determined to address and problematize race based medicines specifically for the horror I believe it was. I was determined to use my horror film as a tool to expose race based medicine as monstrosity. I was determined to explore race based medicine’s relationship to ghosts and monsters, and use my research, by means of film, as a device for education.

### **Race Based Medicine as Monstrosity**

One of my favorite films is an oldie, but goodie. *Rear Window* (Hitchcock, 1954) reminds me of how I came to conceptualize my study on race based medicines into a film performance. Like Jimmy Stewart, there I was, eclipsed in my comfortable little world, when I noticed something ghoulish outside my window. Jimmy Stewarts’ was a real window. Mine was metaphoric, but what I saw was not just window dressing. In the phantom of my imagination I could see that something awful, something sinister, was going on right outside my world. I did not *have* to look. No moral imperative would have been broken if I had turned away. But, I did not turn away. Instead, I looked, and I saw an old monster. It was the staple of horror films, lurking over there in shadows. Near as I

could tell, he was no creepy clown, and he was hardly a werewolf. The monster I saw was man. Man setting his focus on human difference, again.

I moved to another vantage point, this time closer, and looked again. It was still there, placing focus on human difference. Being somewhat separate from it, and yet slightly afraid, I was instantly connected. *This again?* How did the focus on human difference get such border-crossing abilities? From where did it get its longevity? What I saw held its spell over me, and I could see that those who had once been involved, were also quite dead. I kept my eyes peeled, trying to align what I saw with the comfort of my own world. Had the history books I had read all those years ago, been incomplete? So I began my own research and examination of the past, knowing that no matter what I found, I could never really *un-ghost* history?

The above paragraph is my attempt to explain, in both real and metaphorical phrasing, how I came to be implicated with monsters and ghosts of the past. This was a past where lives of colors were considered monstrous, but is it the past? Tell that to murder victim Trayvon Martin. Or Eric Garner. Or Tamir Rice, all murdered because of the color of their skin. Sometimes time does not change much, though when I speak about what I witnessed through the window, I am referring to sentient beings of the past. They served as welcomed ancestral ghosts who led me, as a performance scholar of color, through the process of understanding their lived experiences that were antithetical to westernized history.

What I witnessed through the window of my research was the past, the future, and the myths stuck betwixt and between. It was jarring. After all, no one likes their myths

messed with. What I saw was too far to touch, but too troubling to turn away from. I shrouded my hands over my lens, surveyed the landscape, until I could just make out a group of people staring back at me. “*Tell someone I’m here*” (Galeano, 1992, p. 72). I looked into the watery eyes of the sentient beings, which were not smiling, but instead they were metaphorically howling. “*I am here in the world among you*” (Madison, 1998, p. 173). Was I still at my window, or standing over graves? The metaphor morphed into reality as I focused my research eyepiece, and saw the tracings of a drug that covered people who were already suffering. It was a new, monstrous drug (yes, drugs can be monstrous), called BiDil®. What was so monstrous about BiDil® was that it singled out one racial group. Who? Self-identified African Americans with heart failure. For me, this slapped logic right in its mouth. Why do we need a separate drug for African Americans Did the FDA just sanction socially constructed categories of Hispanic, Black, White, or Asian, as genetically distinct from the biological category of being human? I see you, Carl Linnaeus, hiding there in the shadows. Is it not enough that the health community has already tied being White, with being healthy? Is it not enough that this prevailing version of healthy has been dependent on separating and denying equal access to health to communities of color? If we trace our genetic patterning far back enough we all originate from sub-Saharan Africa, but putting that aside, are we not all just *human*?

Unlike Jimmy Stewart I did not need a pair of binoculars to see the broad and ill-defined salience of race in BiDil®. I knew, through my research in pharmacogenomics, that different individuals have different reactions to pharmaceuticals, but are those different reactions largely tied to race?



Like Jimmy Stewart, I kept watching, and watching until my unrelenting curiosity finally discovered a staggeringly wide industry problem that, previous to this research, I did not know what was happening. I strained to hear the voices, and in time, I heard one, and then another. And eventually, another. They were sharing their narratives with me. Narratives that were masterpieces, many of which had not been heard by many. Of course it was I that lent these historical voices verisimilitude, but each voice seemingly had a distinct identity. Theirs were the voices of the dead, without the limitations of language, but of course, we do not need language to identify pain. They were making me aware of the collective damage to the race, a race of people that look just like me.

I caved in a bit under the weight of the awareness of the damage that had already been done, as well as by my own speculations on how things might unravel in the future with racialized medicines. I found myself urgently concerned with it, so I began nibbling around the edges of the FDA's unprecedented approval of BiDil® and haunted the history of race specific drugs.

The history of racialized medicine is littered with examples showing race based medicines have very little to do with actual medicine. Some might scoff at the fact that racialized medicine underlies the current system of health that continues to haunt America. The work in this study, including my film performance, is a vigilant form of resistance, toward the goal of ending the hauntings of race, health, and medicine. Author Avery Gordon (1997) notes, "haunting is a very particular way of knowing what has happened or is happening" (p. 8). This is true for the nagging memories, the hauntings in

our personal narratives, and it is also true for films about monsters and the monstrous others of medicine.

Bolted to a focus on human differences and sutured along a landscape of racial lines, America chain smokes with race based medicines. Our dalliance with racialized medicines is a complete divorce of what most red-blooded, blue-collared Americans would perceive as fair and equitable behavior. Yet here we are, slow dancing with it. Constructed out of macabre fascinations, the beasts of racialized medicine, responsible for social inequalities, also sanctioned letting men rot in the notorious 40-year Tuskegee Syphilis experiment that went horribly awry. Jones (1993) notes, that the ultimate purpose of the Tuskegee experiment was the hope of proving that syphilis was a different disease in Blacks. Instead the experiment showed the expression of syphilis was not uniquely racially different. The illness devastated Blacks' internal organs, in the same way it did Whites. How disappointed the monsters of racialized science must have been when faced with this grim reality.

Prior to the Tuskegee Syphilis experiment, racialized medicine reared its ugly head in a hodgepodge of behaviors. In 1845, identity-stealing and noted Dr. J. Marion Sims began race based experiments on enslaved African American women who endured vesicovaginal fistula—a tear in the opening between the vagina and bladder that can take place after childbirth. Fistulas made slave women unfit to work in the fields, but fit enough to stay close at hand, to cook, and clean. Is it any wonder that in the famous speech known as “Slavery and the Irrepressible Conflict”, the great Frederick Douglass (1860), referred to slavery as America's pet monster. Then, raising very few eyebrows,

the same race based medicines haunted the monstrous process known as Mississippi Appendectomy—the sterilization of lesbians and women of color without their consent or knowledge.

When I first learned of BiDil®, I wondered what had kept this important pharmaceutical, stained with race, below the surface of my awareness. How did this particular monster bury itself? I knew I would unbury it, as a part of my study. I would speak to the divide of race. As an artist, I have an activism slant to what I was undertaking. I would do something to challenge and possibly even change existing power relations. I also would speak to the monstrosity of health, and to the monstrosity and complicity of human beings. In so doing, I elevate public discourse about the existence of a race specific drug, while raising awareness about other race specific ghost houses of medicine. I up level awareness for those members of the community that are completely unaware of the deafening societal silence of history on the issue of their cultural past, just as I had.

Given these ambitions, it seemed to me that a good starting place would be to have an intimate dialogue with the dead. So I journeyed back to the past, and re-united with the seething, otherworldly presence of my kin, and grappled with the slipperiness of handling snapshots of race manifesting itself as health. I found a way to record memories of lived experiences from the dead who were either trying to teach me something, or trying to frighten. I found my way through film. I called the dialogues I had with the dead, radical, methodological, epistemological, ontological, and deeply excavational modes of inquiry. Of course, others may simply call those dialogues, research.

From the outset, what was fascinating for me about this study is the opportunity to examine the brokenness of a single race specific medicine, despite its supposed efficacy. Inspired by film performance studies, I focused my lens on America's great unfinished argument about race, and looked at it through the aperture of monstrosity. If one buys the fantasy of race, you can see the liminal position race shares with the supernatural world of ghosts and monsters. Ghosts and monsters will not stay dead. Race issues will not die. Ghosts and monsters will not go away. The same can be said about racial concerns. Ghosts and monsters press against windows, open doors, uproot, topple, and demand to be heard. So it goes for races of people. Thus, we have rounded the corner to the horror film, a byproduct of my research, called *The Colored Pill*.

*The Colored Pill* film shows that the only thing more deadly than a ghost whose racialized health story has been willfully ignored, is a race of people who have had the same experience. Though potentially beneficial, there has been limited scholarly research on African American films with an emphasis on race based medicines, and even fewer on these films with a monstrous tilt.

One of the most notable examples of how race and the presupposition of difference continued to shape American medicine was the approval of BiDil®. Could it be that the field of racialized medicine has remained politically disengaged from the human struggle for good health? What physician, in their right mind, would ever admit to engaging in the unethical practice of systemic health injustice by injecting racial science, or even racial superstitions, into medicine?

Not forgetting that bioethicist Sandra Soo-Jin Lee (2005) labeled the approval of BiDil® as racial profiling in biomedicine; much of the idea of race is as venomous in health as it is in horror films. Racial profiling in medicine was molded by barbaric scientific racism, deference, and centuries of mortal fear. Yet, the topic of ghosts and scientific racism is so monstrous that for both topics, there remains a preponderance of social powerlessness and exclusion, to the point of near invisibility. If the argument is that being human serves as proof of our embodied hierarchy in the world, then the existence of ghosts who dwell outside the boundaries of humanity and scientific racism, serves as a counterargument.

### **Scientific Racism as Monstrosity**

Despite its title, *The Colored Pill* is not just a performance of horror about a pill for African Americans. Neither is it solely an African American story. The film is a ghost story. It is a story about monsters. A resistance story for the unseen. As a ghost story, it is a highly symbolic recording and remembering of that which haunts society. Because it is a ghost story, it is rich with cultural artifacts. Because it is a ghost story, it shines a light on human/nonhuman boundaries in society. But, it does not stop there. The film is also the study of the monstrous. It is a study about monstrous people, and about monstrous, abnormal science. It is about the paradoxes and contradictions of the most abnormal science of them all—racialized science. By studying racial science I witnessed a connecting rod between myself, Carl Linnaeus, and his historical classifications.

The narratives of the monster/ghosts in my film were rooted in research where I uncovered specific instances of racialized science. Racial science was made monstrous

when it placed Sara Baartman on freak show spectacle as the *Hottentot Venus*, and because she was from the South African Khoi tribe, was therefore, classified by Linnaeus as *homo monstrosus*. After her death, blurring the line between science and decency, Sara Baartman's sexual organs were put up on carnival-esque display. This seemingly counterintuitive relationship between race and health was not the first time this kind of thing took place.

Author Harriet Washington (2006) skillfully documented the horrors of racial science when she described the terrifying instances of real-life body snatchers and illicit night doctors. Washington (2006) spoke of actions taken against African Americans that allowed medical students to study their anatomy in a way that put fictional horror narratives to shame. The horrors of racial science castrated Black men at the State Hospital for Negroes in Goldsboro, North Carolina. The horrors of racial science appeared again at the hands of the Indian Health Service physicians who forced sterilizations on Native American women. Featured in the film, *The Colored Pill*, racial science was the reason behind the sterilizations of African American women. Spending large amounts of public dollars, this practice was backed by the Federal government. Racial science was on display during the World War II chemical experimentations performed on American troops of color.

To experience these incidents, I needed to conjure up the ancestors, and cross a few borders. To hear the voices behind these incidents, I needed to transcend time/space boundaries. Toews (1998) explanation captured my thoughts when he wrote of the need to, "conjure up the world of the departed spirits so that they may speak to the inhabitants

of the present with their own voices” (p. 535). Misfit for the world, monster/ghosts demand the audience examine the conflict of a presumed truth. Benjamin (1977) ventures, “Truth is not a process of exposure that destroys the secret, but a revelation that does justice to it” (p. 31). In the case of creating my research film, I revealed the truth that would do justice to an out-of-joint history of racial science that had long since descended into the dark, cold cellar where it nestles among the cobwebs.

Seeped in monsterdom, is the case of the racialized pharmaceutical BiDil®. In its approval, not only were communities of color treated as monstrous, but the science used to propose a new way to strengthen racial stereotypes was also monstrous. The power behind this type of science excited a devoted following of groupies, scientific monsters known as pharmaceutical companies. The thrill of that particular scientific monster was that, instead of inspiring fear in the shadows of the larger social context, it seemingly inspired fearlessness.

It is fair to say that the monster of scientific racism, the one that rests inside of BiDil®, is not a flesh and bones figure. Rather, that particular monster is a reflection of the thoughts and feelings of society. The spoken-out-loud narrative we tell ourselves about scientific racism is, *that was then*. We tell and retell ourselves that the depth of that kind of unremitting savagery no longer exists. We tell ourselves those are nightmares of the past, albeit the dreams of Linnaeus. But, what if the things we tell ourselves about the outdatedness of scientific racism, are just mythic narratives? How do we slay the monster we have let into our house? What if, despite our amiable facades of tameness, the bigoted things that happened *then* are still happening now?

No one wants to be labeled a bigot. In my view, most people are not racist at all. We see that so clearly on one hand when we champion freedom, yet on the other hand, we complicate the problem of the big python in the attic by denying it. Unfortunately, despite unprecedented access to historical knowledge with the click of a mouse, most people would deny, or minimally resist, knowing that our health system has been colored by inequalities—past, present, and possibly even into the future. I wish I could say these behaviors are rooted in ignorance, but I suspect they are tied to narcissist indifference. We continuously cover up the victims of science in what author Alice Walker (2004) calls, “the mud of oblivion” (p. 374). The mud of those inequalities, from racialized victims, continues to ooze and then cake across the re-waxed floor of history. Why? Because most people are woefully unaware of the fullness of history. Ironically, we are quick to argue, but slower to question. We are eager to be entertained, less enthused about being educated. In fact, there are those who would rather fill gaps in their knowledge with nonsensical convictions that they *already know*.

Paradoxically, BiDil® was about protecting a specific, scientific idea of what it means to be African American. In the creation of BiDil®, it seems to me that science indicated that Black bodies are somehow unsuitable for mainstream pharmaceuticals. Using White bodies to calibrate norms is not only monstrous, but creates a pharmaceutical merry-go-round. Only, there is nothing merry about it. If we categorize White bodies as the norm in health, other bodies swing *outside* that norm. Once you swing other bodies outside the norm, you justify a need for medical interventions for Otherness, in this case, race. When you create medical interventions for race, beliefs



about our sameness are altered. Once beliefs about our sameness are altered, race as a social construct carousels back to race as a biological construct. This opens an antiquated, revolving door to what looks like science, but is actually racial science.

Unpacking racial science, author Henry Louis Gates, Jr. (2019) describes it as, “the use of ostensibly objective measurements of difference to define race and race characteristics... to prove fundamental, natural, biologically based essential differences between black people and white people” (p. 56). The science of race aka scientific racism has a long history in using the irrepressible appeal of race to focus on human difference, which supports social stereotypes. Why? Proven by the work of Carl Linnaeus, once a so-called medical fact or social stereotype is connected to race, it is tenaciously resistant to evidence that contradicts it.

By misstating medical facts, the medical community exercises very little reflection on the silent past, and misstates their own contributions to widely shared communal knowledge. Hatch (2016) asserts, “Scientific racism consists of discourses and practices that serve to explain and justify social inequalities as the natural outcome of hierarchically organized biological difference understood principally as racial difference” (p. 62).

The horrors of scientific racism as monstrosity reveal certain truths about America, and the tight sallow skin of American history. Scientific racism as monstrosity can be pathologized as America’s *Frankenstein*, complete with neck bolts, colored face, and sutured body parts. Film can be a type of monstrosity, in the same way that scientific

racism is. In the horrors of scientific racism, just like in the horror genre of film, we see something familiar, in that which is unfamiliar.

### **Film as Monstrosity**

The element of being haunted has been analyzed in the vast spectrum of filmmaking studies. Horror films are full of this element, but surprisingly, hauntings have also been discussed in terms of racial and colonial displacement and identity (Bhaba, 1996; Gordon, 1997; Gunew, 2004); as well as in studies of trauma, memory and mourning (Gordon, 2008; Rosenberg, 2010).

The topic of hauntings, ghosts, and race fascinated me so much that I knew I wanted my research film performance to reflect all three. I ensured that my film embodied a supernatural, spectral quality because both the research and illness narratives, in general, possess those qualities. Kröger and Anderson (2013) illuminate, “Film, as a medium, lends itself well to spectrality, perhaps better than the written word. Just as a ghost is a reminder of a person who previously lived, images caught on film remind us of life” (p. xiv).

In thinking through how society might enjoy a just future, Derrida (1994) points out that our readiness depends on our ability, “to learn to live *with* ghosts” (p. xviii). Hauntings are pervasive in nearly every mist-shrouded folktale, myth and boogeyman story, and film is there to swiftly document every one of the ghostly depictions. Utilizing the enthrallment with our fear and love of the unknown, the netherworld of horror films are heavily slanted toward spectral reminders. The parallel world of film—parallel to reality—creates a tension of dropping us into the loophole of a type of hyper-reality,

being both *there and here*. Why? So we can view the unwell and cursed family, live within the inhabited walls of a haunted house, watch the coming and goings of uninvited poltergeists, and experience hauntings caused by race, all from the safety of a velvety, theatre seat.

Brogan (1998) calls *cultural hauntings*, ghosts that haunt histories of colonized communities. For Brogan (1998), the term refers to the, "ghostly presence of colonial slavery appearing again and again, generating disturbance and unsettledness" (p. 132). Ipsen (2016) called them, *colonial hauntings*. I prefer the term *racial hauntings*, because that phrase hints at societal anxieties, as well as victims of racism. Racial hauntings evoke apparitions of individuals, no longer shaped by a colonized past (though colonialism has not yet disappeared), but continuing to exist in a more contemporary context. As a scholar, I know how unusual this sounds. Even Derrida (1994) opined that traditional scholars do not believe in ghosts, yet even he considers "the scholar of the future [capable of] thinking [through] the possibility of the specter" (p. 176). I consider myself that scholar of the future spoken about by Derrida, and acknowledge that the disturbing presence of racial hauntings in films is the revenant embodiment of racial Othering within the present culture. In films, and within the dominant culture, race is conjured up as the monstrous thing that, with increasing regularity, needs to be tamed or eradicated.

Chilling examples of racialized hauntings extend from the ghostly encounters in author Ralph Emerson's (1952) *Invisible Man*, to the apparitions in author Toni Morrison's (1987) *Beloved*, but films can also be quite monstrous. With a predominant

African American cast, filmmaker Jordan Peele's (2019) racially-charged horror, *Us*, upped the topic of Othering to include a family of monstrous doppelgängers. Racialized ghosts in film serve as reminders of how much race has taken up residence in nearly every area of society.

### **Horror Films as Monstrosity**

What makes horror so monstrous? Author Noël Carroll's (1990) innovative treatise shares that horror is "marked by the presence of monsters" (p. 15). I agree that every good horror film needs an equally good monster. Carroll (1990) posits that horror monsters are a disgusting fusion of the living and dead (i.e., vampires, zombies) or human/inhuman (i.e., werewolves). With all the trouble in the world—race relations, climate change, violence, inequalities, poverty, and terrorism—don't we have enough on our IRL plate to fear? The door is ajar as to why do we seek out vampires, zombies and werewolves—staples in horror films—to make us more afraid? Is it true, as author Stephen King (2004) said in an interview, that in viewing horror movies, "we are daring the nightmare." Do we thirst for horror because some of us are thrill seekers, while everyone else are scaredy-cats? Are we distracting ourselves with horror films out of boredom? Not Aristotle, Jung, Freud, or even King (mystery author, Steven King, that is) can tell any of us precisely why some like to sit in the dark and allow ourselves to be frightened, while at the same time, others simply cannot stomach the concept. What are the roots of horror, and how does it work when we, as the audience, know that the terrifying things we imbibe in on screen are not real? After all, these things aren't really

going to *get us*. Is it as simple as what Anthony Perkins (Norman Bates) said in the film *Psycho* (Hitchcock, 1960), “We all go a little mad sometimes.”

After conducting a study on children and adult emotional responses to viewing horror films and television programming, Buckingham (1996) learned that adult horror fans tend to experience fear as being, “synonymous with pleasure” (pp. 111-12). Is that it? Might fear and monstrosity give us pleasure?

The answers to these questions, of why we seek out horror, reveal a fair share of paradoxes. The explanations for these questions are intricate and evasive. No evolutionary biologist, evolutionist, communication theorist, psychologist or psychiatrist, nor any biochemist, neuroscientist, or mythologist can put their finger on precisely why people thrill to the sensation of films that feature chainsaw-wielding crazies and monsters. The reason these esteemed professionals cannot pinpoint the exact cause is because, in my own view, the reasons vary, individual by individual. And while no one has a single, all-encompassing answer to why so many people love horror, they probably would all agree that horror asks some pretty difficult questions. In the case of *The Colored Pill*, the horror genre asks the question, why would anyone medically treat individuals based on their race?

Among the different types of horror are science fiction horror, as in the film *Invasion of the Body Snatchers* (Wanger, 1956); vampire horror, like *Twilight* (Godfrey, Mooradian, & Morgan, 2008); race horror where the monster is typically racialized as African American, as in *Night of the Living Dead* (Streiner & Hardman, 1968); and slasher horror like *Friday the 13<sup>th</sup>* (Miller, 1980), to name a few. Zillmann and Gibson

(1996) posit that, “the modern horror film is merely the latest form of storytelling that has been used since ancient times to describe dangerous exploits” (p. 15). Employing other views, Landsberg (2018) opines, “Horror’s true radical potential derives from its ability to depict the unthinkable, to materialize the immaterial” (p. 632). Wetmore (2012) offers, “‘Horror’ is a specific genre, but one that finds its boundaries blurred, and with numerous subgenres” (p. 5). Taking the opposite approach, critic Douglas E. Winter (1988) ventures, “Horror is not a genre, like the mystery or science fiction or the western ... horror is an emotion” (p. 12).

In my view, any attempt to define horror is like trying to anchor oneself to a soft blanket of snow. No matter how deep it is, it will not last. Whether the genre of the film is a social thriller, or a slasher horror, Pendery (2017) reasons that, “one person’s horror is another’s thriller, is another’s drama, is another’s science fiction, is another’s fantasy, is another’s fairy tale” (p.149). My total agreement with his different-strokes-for-different-folks assessment of horror is indeed the reason why, for this study, I have used the genre titles *horror* and *thriller* interchangeably. In some places, I simply use the phrase *thriller/horror*. Another reason for my use of the thriller/horror phrase is because *The Colored Pill* is closer to a social thriller, with its psychological connotations, than it is to a true horror that may feature blood and gore.

Author Robin Means Coleman (2011) ventures that horror, “... is one of the most intrepid entertainment forms in its scrutiny of our humanity and our social world” (p. 13). Whether we view horror as entertainment, or not, the one thing all the subgenres of horror have in common is the element of fear.

Whether we view fear as pleasurable or painful, we all have at least one fear or another. Driven by a hard-wired flight-or-flight response, fear can kick us right out of our inertia, or it can be somewhat benign, as in the case of socially constructed non-instinctual fears. In an unpredictable world such as ours, without the experience of being afraid—instinctual or non-instinctual—we probably would have experienced real trouble in staying alert during the evolutionary process. After all, in the past, if we did not have a real fear of lions, tigers and bears (*oh, my*), we would probably have ended up being a very tasty dinner for one of them.

How do we nail down fear when examples of what is scary are so peculiarly subjective that one representation can elicit nail biting, as it did when I viewed *The Babadook* (Ceyton & Moliere, 2014), and another representation can elicit belly roll laughter, as I did when watching children's horror, *Frankenweenie* (Burton & Abbate, 2012)? Whether monsters of horror are laughable, repulsive, or even animated, as in the case of immersive horror video games, fear itself, is universal.

What happens when we are afraid? What biochemical behaviors are taking place? In my view, the minute we are unsure of anything, or we are positive we do not know something; we might as well go ahead and cue anxiety and imagination—characters that I view as kissing cousins. If we ponder long enough on the unknown, the imagination is engaged, and then, either solutions will be created, or uncertainties will be enhanced. This is monstrous because if we are uncertain long enough, fear creeps in. The greater the uncertainty, the greater the fear. Explaining the human fear response, Pendery (2017) states:

It stems from a single bodily network: the subcortical limbic system of the brain. This is the emotion and memory center that includes the amygdala, hippocampus, thalamus, catecholamine systems that control the release of essential hormones and neurotransmitters, and other structures that are foundational to emotional experience. (p. 150)

Now, that's a mouthful of words to describe the experience of increased heart and respiratory rates, which prove that fear, can be scientifically measured. In horror films, our fear of death is the great equalizer. It is not just that we are afraid of our own death, audiences feel afraid when other people face death, or at least that's what filmmakers like to believe. Whether the death is by meat hook, jagged edged blade, or even by homicidal vehicles, they all mean the same thing for filmmakers—accessibility to audiences' fear response. One of our greatest fear responses, in and out of the theater, is the fear of death. By association, that includes the fear of the dead. Anyone who has ever experienced the gradation of grief knows that the dead do not confine themselves to the worn safety of our memories. Sometimes, after experiencing a death, with every fiber in your being you could swear that you *feel* the dead one in the room with you, even when that very room is an absent space. What dead thing can walk into an empty room? Answer: monsters. Ghosts. And, if you tell anyone about seeing the dead ones, people will simply believe that grief has mapped its way to your mouth, or to your mind, and you sure as heck do not want to be viewed as deranged. So you gain your wits about you, you go away, and you experience your monsters and ghosts, in silence like any other reasonable person. But, why are they here? Were they here?

Many believe the dead are envious of life. This creates a great plot twist for the monstrosity of horror films. Film scholar Stuart Kaminsky (1974) suggests that, "horror



films are overwhelmingly concerned with the fear of death and the loss of identity in modern society” (p. 101). The dead are often consumed with anger, and skillfully show their anger by knocking over vases and lamps. In horror films, the dead often want revenge, but if we actually literalize monsters and ghosts, we would find that one doesn’t have to be a previous occupant of the world to be envious, to have an angry attack, or even to knock over vases and lamps. All one has to do is look through the peephole in their front door, see a creepy eye staring back, to be reminded of the monstrous entities that live right here among us. Ask any stalker victim if only physically dead humans haunt the living.

I recall a monstrous haunting from a once popular film. Danny, a lonely boy in an isolated resort hotel, pedals his low-riding tricycle through several extremely long corridors. Rounding a corner, he encounters two twin girls waiting for him at the end of the hall. “*Hello, Danny*” they chant in unison (Kubrick, 1980). Terror steals his voice. The boy, a gifted psychic, sees flashes of the girls as corpses—slaughtered and bloody. The girls, what he now knows are actually twin specters, speak, “*Come and play with us ... forever and ever and ever*” (Kubrick, 1980). Reeling, Danny covers his face with his hands, and then peeps at the ghostly girls through gaps between his fingers. Now, that’s a chilling and monstrous performance moment, torn from filmmaker Stanley Kubrick’s well-told horror film, *The Shining* (Kubrick, 1980).

What made the film moment so monstrous? Is it the isolation of the hotel? Is it the isolation of the young boy, and his soon-to-be-taken innocence? Is it the twin ghosts, and

the gory details of their demise? Truth is, any one of these deliciously monstrous elements could make an audience member shudder.

To help make the audiences in my thriller/horror, *The Colored Pill*, squirm and tremble, I chose to incorporate into my research, twin specters—truth and the unknown truths of history. I told the story through uncontrollable apparitions—as true-life figures unfairly persecuted by true-life humans. In this respect, my study is about ghosts. Not just any ghosts. Ancestral ghosts who once walked the earth and were killed for their monstrousness. Within the context of African American folklore, the appearance of ancestral ghosts who exorcise deeds of a terrible past, are not all that uncommon. As ghosts, their hauntings pivot on being used for human experimentations, or on the extreme violent dualism of being treated (medically, and otherwise) as marginalized humans.

Author Toni Morrison (1988) said, “Ghosts are not difficult [to write] because everybody believes in them, even those of us who don’t believe in them” (p. 46). Like Morrison, writing a film metaphor about monsters and ghosts was not difficult. Finding a way to interconnect ghosts, colonial ancestors uncovered in my research, into a history film performance, was challenging. After all, what I was performing was not some fantastical fiction about dead people, but rather, it was an investigation of scholarly research that just happened to be full of horror. Gordon (1997) spoke about the investigation this way: “The ghost is not simply a dead or a missing person, but a social figure, and investigating it can lead to that dense site where history and subjectivity make social life” (p. 8).

Film has the ability to break through previously held views and make visible everyday social realities. No film, in the horror genre, ruptures the thick façade and exposes the monstrous truth of the way things in our world really are, more than the social thriller. Teasing out social turmoil, in social thrillers or horrors, the monster is often situated within our society. Filmmaker Roman Polanski's social thriller *Rosemary's Baby* (Castle, 1968), with its plot centered on the monstrosity of a fetus, ruptured discussions and asked socially-driven questions about motherhood as well as about patriarchal oppression.

Like *The Colored Pill*, another social thriller that took on a racial subtext was the film, *Night of the Living Dead* (Streiner & Hardman, 1968). In that film, a Black man survives a zombie apocalypse, only to be killed by White police officers restoring the peace.

I see photographer Walter Benjamin's (2008) compelling insight about photography and what he radically refers to as "optical unconsciousness" as being similar to social thrillers. For this reason, while Benjamin (2008) is clearly speaking about photography, I see his insight as fitting for this discussion. The monstrousness of social thrillers is based on the fact that what we believe we see is not always the only thing that is there. In actuality, we are seeing so much more, for in social thrillers, what we are typically seeing is our self. Ghostly inhabitants and sightings in social thrillers, turn out to coincide with seeing things that were within the characters all along. In so doing, social thrillers summon us to come to terms with and make visible our own presumptions, frailties, and beliefs.

While the idea of the photographic instrument serving as a method to produce visibility is not new, the revolutionary aspect of *optical unconscious* is a kind of seeing-but-not-seeing behavior important to social thrillers, particularly where there is the presence of ghosts in the film. One of the reasons we often do not recognize film ghosts, as ghosts, is because we recognize ourselves in their normalness. The Other, in most of our minds, should be nothing like us, which is often the reason why viewers struggle with figuring out who the real monster is in some film plots. I contend that filmmaker Jordan Peele (2019) skillfully pulled this concept off in his social thriller, *Us* (Blum, Cooper, McKittrick, & Peele, 2019). The film is extraordinary in that it concerns duality, monsters (aka The Tethered), and a very frightened Wilson family who were being stalked by doppelgängers. While there may not have been scary razored gloves like in the original *Nightmare on Elm Street* (Shaye, 1984), in the horror film *Us* (Blum et al., 2019), there were scary, monstrous artifacts—scissors. The terror imagined by Peele, also expertly tethers the topics of Othering, alienation, and difference, and in these connections, reveals the true monster. Not the horrific, grotesque looking individual, but rather, Peele instructs that the true monster could be the one whom we cling to, clutch onto, and are scared alongside. Intelligently, the film's title, *Us* (Blum et al., 2019), testifies to the fact that we are going to be nudged into seeing ourselves as the Other.

In the horror film, *The Others* (Bovaira, Cuerda, & Park, 2001), viewers fail to initially recognize the real ghost, because it is too unsettling to accept the ghost as a social figure who is just like us. Gordon (1997) suggests, “Hauntings makes manifest something that we are in danger of forgetting, or not even noticing” (p. 8). As in

photography, the deployment of this same kind of film trick, was to have viewers come face-to-face with literal and metaphoric hauntings, which in their own life, they are blind to.

In creating *The Colored Pill*, I too, chose to have viewers come face-to-face with both literal and metaphoric hauntings, from history, which, in their own life, they were blind to. Yet, *The Colored Pill* is a different type of racial history film. In many ways, it is a type of social thriller. It is an issue-driven film, in which I have tucked social messages that not only expose racialized health, but also reveal the complicities at work in maintaining a single-dimensional view of history. While I did not want my research film to feel heavy handed, it was important to me that I create the kind of performance that would allow audiences to observe the social phenomenon of Othering. I did so by uncovering the medical industry's complicity in sustaining racial oppressions, and also by putting the spotlight on the monstrosity of some medicines and treatments.

The ghosts depicted in *The Colored Pill* may have started their lives as powerless victims, but by the end of the film, they are anything but helpless. In fact, the way they take control of the living hopefully helps the audience, to reimagine them. In doing this, I know it does not completely challenge cultural notions about film ghosts, but it does help the audience to create questions about ghosts of inequalities.

Creating a horror that is also a social thriller, allowed me to test the boundaries between entertainment and education, while not sugar-coating the appalling number of casualties actually accumulated by race specific medicine. In its creation, the film contests the universality of western history, by showing the monstrous side of medicine

that has participated in Othering. This side of medicine has consistently been harbored, hidden, and disguised.

In making *The Colored Pill*, I thoughtfully considered filmmaker Jordan Peele's 2017 brilliant social thriller, *Get Out* (McKittrick, Blum, Hamm Jr., & Peele, 2017), and the way he meaningfully used film performance to show the monstrosity of Othering. In *Get Out* (McKittrick et al., 2017), Peele put on display, tensions in racial hierarchies that exist within our culture. The film *Get Out* (McKittrick et al., 2017) is chock full of racial Othering of the main character. As illustrative examples, the African American main character in the film is called *boy*, and in yet another scene, he is auctioned off. While the film also incorporated important scenes about assimilation and the backdrop of Othering, particularly noteworthy was *the sunken place*—a space where the paralyzed-via-hypnosis main character is suspended, all while seeing other people gaze down at him. In my view, *the sunken place* was a film masterpiece. It symbolized the monstrosity of Othering, as it encapsulated a black hole space of isolation, reduction, and exhibition, through which the man of color was viewed. Calafell (2015) ventures, “cultural anxieties and fears around Otherness, whether they are about race, class, gender, sexuality, body size, or ability, manifest themselves in representations of both literal and symbolic monstrosity” (p. 4). In *The Colored Pill*, I symbolized monstrosity through the characteristic of bias. Using the bias characteristic, I was able to show how it drives anxieties and specifically drives fears that continue to terrorize and repress individuals. What *The Colored Pill* achieves is the exposure of the monstrous evilness, fears, and subsequent violence against African Americans in this country, defined by Othering them in health and medicine.

## Human Monster as Monstrosity

“But these weren’t the kind of monsters that had tentacles and rotting skin, the kind a seven-year-old might be able to wrap his mind around—they were monsters with human faces, in crisp uniforms, marching in lockstep, so banal you don’t recognize them for what they are until it’s too late” (Riggs, 2011, p. 17).

In this research, I was haunted—metaphorically—by the dead. I demystified them and brought them into dialogue. I fully unleashed the dead monsters, talked to them, and allowed them to walk among the human monsters that dwell on this plain, before laying their spirits back down to rest. I conversed with the distorted monster/ghosts that hovered over the long shadows of racialized medicines in our history. After all, in discussion with Roberts (1995), our historicity defines what we are. In definition of us, these distorted shadowed selves are convexed between the recognized and the unrecognized. Therefore, history becomes concaved as a threat to humanity, and becomes the fun-house mirrored reflection of a human monster.

What we precisely mean when we use the word *monster* is not an easy question to answer, especially since monsters can be both literal and metaphoric. The literal, blood-slurping monster has been defined for us in the most graphic of depictions in films, television programs, and literature. Yet, there are so many metaphoric monsters—monsters placed in scare quotes—including in the workplace, that we actually have an online job board that uses the name. A monster by any other name will smell just as ... awful? Is there more than one kind of monster? To start this part of the discussion, I begin with the etymology of the word *monster*.

Asma (2009) elucidates the English word for monster, derives from the Latin word *monstrum* which relates to the root *monere*, meaning, “to warn” (p. 13). Cohen

(1996) suggests that, “the monster signifies something other than itself: it is always a displacement, always inhabits the gap between the time of upheaval that created it and the moment into which it is received, to be born again” (p.4). Paradoxically, the specters of death in my film spoke to the larger social structures in place that produced ghosts. Grusin (2015) argues, “The human has always coevolved, coexisted, or collaborated with the nonhuman” (pp. ix- x). In my imagination, the perpetually strange monster/ghosts co-exist with us as experts seizing our attention.

With a monster creation in mind, for *The Colored Pill*, I searched across the deep blue sea for the most disgusting, scariest of the scariest creature. I took a long voyeuristic look, searching for the perfect monster through a side-show catalogue of blood-slurping vampires with unnaturally long fingernails, carnivorous zombies, and soul-less giants. I wafted through a brood of monstrous dragons, sea serpents, and pointed ear hunchbacks. I searched past two-headed babies and head less men. I roamed and followed the footprints of the most treacherous beasts in all the land. I searched well beyond the grass-eating behemoth (Job 40:15, King James Bible), until I finally found my film monster. This is where it really got interesting, because up until this point, I was afraid I would have to conjure one up, yet once discovered, it was hardly worthy of even an *aha*. The monster was there all along, not hiding, but rather looking back at me in plain sight.

Who is the animalistic, teeth-gnashing, eerie creature from which we instantly recoil? The answer. The human monster, who else? Winding an endless melody, the human monster seduces, attracts, and yet scares us so much that we want to fight it. Nietzsche (1973) said it well: “Whoever fights monsters should see to it that in the



process he does not become a monster” (p. 84). What benefit is there in fighting a monster, if we are only going to become the monster? For many viewers of horror, the uncomfortable truth is that the so-called monster is often already a self-portrait, a dim reflection of us.

In filmmaker Jordan Peele’s horror film, *Us* (Blum et al., 2019), we were reminded that as we chase the monster down the rabbit hole, we should not be too surprised to find that we may end up holding hands with it, that is, holding our own hand. In many ways, we are the monster that has survived, despite the odds.

After all, not all ghosts and monsters are shrouded in white, banging chains and dripping saliva through “gold teeth and fangs,” nod to entertainer Kanye West, and the lyrics to his song, “Monster” (2010). Peeking out from the shroud (or 3-piece Brooks Brothers suit), the one dragging the film character by their feet into the dark world of a basement, is often another human being—a human monster.

Asma (2009) reasons, “The term monster is often applied to human beings who have, by their own horrific actions, abdicated their humanity” (p.8). By that measure, the human monster plays like a type of ghostly, disfigured doppelgänger—a double walker, a shadow of the self. It is actually not that unusual. How many people publically seem fairly normal, but privately take on unusual behaviors? Maybe, for those individuals, their monsterdom is just waiting for the right moment to shine.

The behaviors of the human monster, however, tend to go against social norms. This was on display in the horror film, *The Shining* (Kubrick, 1980) when the father hollers to his wife, “Wendy, I’m home!” all while searching for her with an axe in hand. In

the film, *The Sixth Sense* (Marshall, Kennedy, & Mendel, 1999), a young boy sees ghosts, but the real monsters are the humans. As the narrative goes, the human monster in that film lethally poisons her daughter. The irony of these film doppelgängers is at first glance, none of them appear to be grotesque psychopaths, or sexual deviants. Of course, later their dual identities can no longer be hidden, and their monstrousness is revealed.

I continued in that vein, in the creation of human monsters in *The Colored Pill*. My film monsters appear to be everyday humans (full transparency, every character in *The Colored Pill* film is a non-human that appears human). The monsters are not grotesque, not maniacal, and not even in possession of over the top appearance. Knowing that we are socialized to distance ourselves from the hooves of others, I turned this monstrousness on its head, and embodied otherness in the film. In this respect, I was able to easily show the interconnectedness of nonhumans and humans. I was also able to have the viewers face the possibility that the monster does not always lie in the darkest edges of the forest. In so doing, I hoped that viewers might recognize their own dark parts, their own Otherness. This gave way to the audience recognizing the dark shadows between the parts of each of us that are human, while it simultaneously marks the imbricated parts. All of these human parts that make up our profound inner, often undetected and unnamed dividedness—are actually our uncontainable human monstrousness. This divided subjectivity, the unchecked versions of us, both mark our threat to ourselves while at the same time, highlight the interconnectedness between us and the other. Therefore, this marks our monstrous nature as being both internal and external.

I wrote my horror thriller to position the characteristic of bias, as monstrous. In *The Colored Pill*, the characteristic of bias functions as both a metaphorical monster character, as well as the name of the main character. By doing so, the real enemy of the film had no physical form, as I believe the real *bad guy* to racialized medicine has no physical form.

I confess that while Cohen's (1996) "Monster Theory" is not the defining supposition for this study, but it does a fine job of drawing a line between understanding a particular culture, and an examination of the fears, and thus the human monster, of that culture.

Francis (2013) explains that "Fear is horror's most precious gem" (p.15). Therefore, Cohen's first theses include the fact that the physical embodiment of the monster, made up of fears of a repressed culture, presents itself as a societal threat. In this, society *needs* its' gem—the projection of a monster. This gem is needed, if for no other purpose than, to have a soft bed in which to plant our fears.

Cohen (1996) asserts the cultural monster is a "projection of (an Other) self" (p.17). In this projection, dehumanizing the other becomes the monstrosity. Fear of the other becomes the monstrosity. Being the monster is not necessarily based on the reflection we see when staring at our mirrored image, but is more about what others see, or do not see, when staring at us. Very little can shield us from that reflection, but being the monster is also about the ill feelings we are compelled to have about ourselves, *after* the gaze of others has been unleashed. In my view, this is the duality of being. It equates

to our first and second births, though there are many more. The one who carries the fear also carries the greatest potential of becoming the monster.

Cohen's (1996) third theses—the monster is not easily categorized—does not speak to the fact that the monster is neither entirely human, nor entirely mythical. The human monster I created as a main character for *The Colored Pill* is a fearful immortal—not entirely human, but not entirely mythical. He haunts the places he has ravaged. In alignment with Cohen's (1996) seventh theses, the monster I created lives his life in the wide open. Drawing connections to the film, the immortal bias character that I created represents the monstrous progeny of a cultural crossroads. He represents biased times in America, and thus, born in the first theses of what Cohen (1996) asserts that the monster's body “is a cultural body” (p. 4).

Film audiences generally expected the monster to be quite fierce, and ugly in appearance. On the contrary, the human monster I chose was rather ordinary looking. Because I was creating a human monster that fits in with his world, I did not want him to appear unnatural, or particularly evil. I considered how, outside the film medium, a human monster wreaks havoc upon the world. I realized that some human monsters are well-intentioned. Some human monsters begin their work in silence, and sometimes adopt a politeness protocol. I considered that human monsters can be internally fearful. They may even have a massive ego, a fixed set of moralities, and are drugged by the kind of unconscious bias that leads them to believe themselves to be color blind. But are they color blind, or intentionally blind?

Notwithstanding human monsters, there exists a good deal of literature establishing the fact that most of us are not, in fact, blind to race. A *Newsweek* (2009) cover story article featured a gorgeous White baby beneath the headline, “Is your baby racist?” (Bronson & Merryman, 2009). The article showed that even infants are aware of differences between racially different individuals. Does being aware of differences make the baby a monster? Is the baby suckling from a racist teat? I am not convinced in the kind of thinking that supports that as the twig is bent, so grows the tree (at least not as it applies to infants). Besides, is there any wonder that an infant can tell the difference in matters of race? Difference is visual. Just seeing difference, in and of itself, does not create the monstrous; however for my film, I created a monster. To do so, and in keeping with the subject matter, I needed to highlight a real-life monstrous character that would neither refuse to acknowledge the preservation of their white privilege, nor be willing to do anything about it.

I decided early on that my film human monster needed to be equipped with a healthy dose of human hubris. To be truly monstrous, my character’s emotive level needed to unnaturally rise when the image of him was assailed, but he needed to believe himself to be good. He needed to be willing to kill to uphold his beliefs. In other words, my monster is a moral monster. Now, that’s a real scare. No fangs. No blue, gelatinous face. No liquid goo coating his skin. But what is under my film monster’s skin is just an ordinary looking humanoid figure, which like many humans is great most of the time, not-so-great when no one is watching.

On the topic of watching, many viewers hold hard opinions about whether or not a horror film actually sustained tension long enough to scare them. Most viewers, with their quite natural preoccupation on the visuals, forget that sound makes up a good portion of the film. In this next section, I turn to the topic of sound and music as monstrosity. Film is most definitely a visual medium, but on equal footing is that fact that film is also a medium of sound. Music and sound have a dynamic relationship with film, and in the case of horror, these elements usher the monster onto the screen. The auditory language of sound in film can successfully soothe, terrify, alarm, and in the case of a sweet melody, can even lull. Film sound can communicate a range of feelings, from gloomy to exuberant. For example, if racial hauntings were expressed as music, I imagine it would sound like the first minute or so of Carl Orff's (1937) monstrous composition, *Carmina Burana*. It goes without saying that horror music is hair-raising. That is as it should be. Cavarero (2009) explains that the word *horror* derives from the Latin verb *horreo* which means "hair-raising" (p. 7). For me, I associate *Carmina Burana* (Orff, 1937) with scariness and fear, elements that perfectly set the audience up for the arrival of the monster.

### **Sound and Music as Monstrosity**

As awesome as our human anatomy is, most people can easily close their eyes, close their mouths, close their noses, close their hands, and, if they engage their emotional resources, they might even be able to close their heart (though this is ill advised). However, without noise-cancelling headphones or some other such invention, there is little way for us to close our ears. We may not be able to believe our own eyes,

but we can almost always believe what we hear with our own ears. Perhaps that is why we experience the mystery known as the cocktail-party effect. In this effect, our ears are tuned to selectively hear our own name being spoken, even in a noisy cocktail party crowd (Cherry, 1953). On a personal note, I once heard the voice of my own child calling me among a playground full of children, many of whom were also yelling the exact same high-pitched, *Mommy*, seemingly all at the same time.

Whether you are underwater, or sticking your fingers into both ears, short of a physiological problem, we can still manage to identify voices, and an assortment of sounds. This is so true, that Stilwell (2001) notes that when watching films, we cannot cover our ears with the same certainty of muting the sounds, in the way we can avert our gaze. In fact, in horror films, closing our eyes to the visual experience may succeed only in stimulating our arousal and boosting the scary ambiance of the film. Words are intellectual, but luckily for filmmakers, sounds are prehistoric.

Before I get ahead of myself, and lest there be any confusion, let me say clearly that I am not a sound artist. I have had no musical training. I have never even had a piano lesson. So why is someone who, by no means is an expert in music, writing about sound? I am a writer. An artist. A storyteller, scriptwriter, and filmmaker. Writing is my song, and because of that, I know a thing or two about creating tension and release in words and on-screen. Therefore, in this chapter, I draw attention to elements like tension and release that are as useful in filmmaking as they are in creating music.

The focus on this study is not limited to film sound. This interdisciplinary study is an inquiry into the effects of monstrosity in film. For example, as a writer, I know about

creating a certain tone to a piece. Music is also concerned with tonality. The written word has an emphasis on language. I have come to realize that music also has a distinguishing *language*. Most scriptwriters desire to achieve a memorable, identifiable quality—an accessible hook, if you will. So does the *melody* in music. Screenplays look for certain powerful combinations. Musical *harmony* is looking for the same thing. In fact, distorting the harmony is absolutely monstrous. Also, it can be said that whether it is in the retelling of a children’s book or the reading of a great novel, stories move to certain beats of time. So does the *rhythm* of music.

Contemporary theorist Michel Chion (1994) shares that music allows film, “to wander at will through time and space” (p. 82). I knew that part of this study would be the investigation of monstrous music, so, naturally I did what music calls for. I listened. The more I listened, the more I realized that what I was hearing did not derive solely from my ears. When I listened intently, concentrating heavily on hearing the sounds, something happened. I realized that I could *feel* the resonance and the vibrations of sounds across my face, on the back of my neck, in my stomach, and even on my feet!

Feeling sound in this way is in keeping with a line of dialogue I have grown to love, written by author Zora Neale Hurston (1928). When speaking about a man who appeared not to be moved by the sound of music in a room, Hurston (1928) said, “He has only heard what I felt” (p. 216). I agree with Hurston that sometimes the thing you hear, explains what you feel. James (2019) reports on *Black Panther* (2018) sound editor/mixer Ai-Ling Lee views, “We used sound to show not just what you see but what we want you to feel” (p. 63).



Admittedly, prior to forcing myself to be attuned to film sounds, I did not focus on sounds, or the feelings that derive from sound—monstrous or otherwise. However, once I experienced the varied sounds in the walls of my film, it changed my entire view on sound as monstrosity, and on filmmaking.

Currently, much ink has been spilled that marries the synchronicity of sound to film, but for my study, I placed sound into a narrower frame. That said, for this chapter, I veered away from a traditional research examination centered in the privilege of what Dwight Conquergood (2002) called *textocentrism*. Textocentrism is a privileged, written form of knowledge. According to Conquergood (2002), text-centered privilege undermines the vast amount of non-written forms of knowledge in non-western cultures. Similarly, scholar D. Soyini Madison (1998) discussed privileging texts by speaking of it as “textual fixation” (p. 277). In alignment with both Madison’s and Conquergood’s thoughts on performance as a strategy to challenge textualism, I leaned into monstrosity in sound and music as a form of knowledge. In so doing, I was not necessarily looking to examine the varied use of sounds in film in general. That would have included examining a vat of natural sounds, unanchored by the human voice box, like waves crashing against the shore, or the drum of thunder made by nature. That examination would also have involved looking at animal sounds, as well as noises employed by the human larynx, like speech, music, and other vocalizations.

Instead, I looked closely at how sound, embodied specifically in horror, serves as a meaning-making tool. In horror, even a sweet lullaby or other child-like sounds can come across as monstrous. This was evident by the creepy children’s music box sound in

Charlie Clouser's (2007) soundtrack and theme for the supernatural film, *Dead Silence* (Koules & Burg, 2007). Similarly, a lullaby came across as anything but sweet in *The Brides of Dracula* (Hinds, 1960).

Most of us are trained to distinguish the kind of hard-hitting music used in a film car chase, from the soft sounds used in a romance. The cacophony of sounds rising to a shimmering crescendo often accompanies films involving a hero. We are trained to discern the hero, just from the music and sounds. The monstrous music in horror films, used to elicit the emotional response of fear, is often much more obvious and straightforward than other genres. Consider the staple of the gothic organ played in *The Phantom of the Opera* (Webber, 2004), used as a device to add a clear, spooky ambience to the film.

In this chapter, I paddle through the waters and under the bridge of analyzing how music and sound functions as monstrosities. By taking that entrance door, I came at the study of sound from a slightly different angle. What was compelling for me, because of its draw from the domain of monstrosity, was the process of purposefully studying sound marking means of expressions by focusing on a phrase I coined, *sound as monstrosity*. This is an area of sound where I have a pointed interest.

In the exploration of sound and music as monstrosity, I look to deepen the conversation about sounds that either create the monster or indicate the malevolent threat of the monstrous. In so doing, I examine sound as a device of fear. Arguing that sound indicates the very presence of the monster, I base my examples on other films in the horror genres, and on the sound structure of *The Colored Pill*.

Truthfully, we live in a world overwhelmed with images. And, let's face it, talk can be cheap. In movie making, the quest for the right music and sound can be both laborious and, in terms of the creation of Foley or the purchase from sound libraries, quite expensive. But no matter the costs, sound can elevate an average thriller into an iconic horror. Most would assume that filmmaking relies solely on visual aesthetics, because sound does not always draw attention to itself. Whittington (2007) reminds us that, "In this age of visual culture, it is important to remember that sound is half the picture" (p. 1). While appropriate visuals have a prominent place in filmmaking, it cannot be denied that visuals have a limitation that sound does not. While image and narrative have an important place at the table, music and sound are the lifeblood of horror films. Ranging from deceptively sweet, to dark and disturbing, music and sound create those heart-palpating, seat-gripping moments where the audience knows they are in trouble.

After all, we can hear what is happening literally behind our heads, even when we cannot see. Despite the fact that, film viewers have an obvious bias toward the orientation of visuals, the patterns of sounds in film can be as easy to follow as the start of the four-note, short-short-short-long classic motif from *Beethoven's Fifth Symphony* (Beethoven, 1804-1808), or music that is much more complicated. But just because we can hear what is going on, does not mean we are necessarily listening.

It is a rare film that does not employ sound. It is also a rare viewer, or in this case, listener, who actively listens to the varied sounds in a film. That points to the masterfulness of the director, as well as to the film editor. While we want the sound to be

appreciated, it should be placed so seamlessly as to *go with* the scene, not necessarily to stand out. Unless, of course, standing out is the desired effect.

In the imaginary world of film, there is an ingrained expectation by the viewer that nothing will interrupt the visceral experience. Yet, as vivid or hair-raising as the visuals might be, what shifts the perceptual framework is the effect of sound. In this respect, sound is a place that helps situate the viewer into the visceral environment.

In addition to being a place, sound is also an in-between place, outside the horror-inspiring frame of what most viewers are paying attention to. Flirting with the visual relationship, sound is a wonderful tool to help tap into the viewer's psychological space.

The phrases I coined, *sound as monstrosity*, and *music as monstrosity*, are the specific acoustemological structure for the monstrous to come into being. Haunted by embodied and disembodied sounds, the music of monstrosity is different from other sounds. What is at stake is the sound, vibrating from one octave to the next, which transposes communicative potential into a type of effect. Here, I am not just talking about the acoustical differences between C and a C-sharp. Instead, I am referring to the emotional notes sounded as a scream, a guttural groan, or the hooting of an owl—sounds that are perceived as monstrous. These monstrous sounds provide a useful anchor to the visual narrative of thriller/horror films. Sound as monstrosity, and thus music as monstrosity, are the elements that ramp up a drama, turning it into a thriller or horror. Most importantly to sound as monstrosity, specific sonic connotations delineate and signify the presence of the other, and/or the presence of the monster. In experiencing sounds and music as monstrosity, the audience experiences cognitive dissonance and an

unfailingly chilling atmosphere is created. This scary atmosphere is necessary in many film genres, but particularly in horrors and thrillers. The creation of this kind of atmosphere takes place even when the audience does not take in the music/sounds at a completely conscious level.

With sound and music as monstrosity, from the beginning of the film, the sound horrifies viewers even before they fully comprehend the plot. When viewers walk away from the dark of the movie theater, they may remember very little about the actual sounds experienced in the film. After all, with its in-one-ear-and-out-the-other nature, sound has a clear ephemeral quality. As in any area of monstrosity—film or interpersonal communication—we may not have perfect memory of the actual words used or total recall of the songs, but what we will certainly remember is the unnerving way the film made us *feel*. In film, that *monstrous feeling* means that sound has done its job. In my view, the shock-and-awe feeling that lingers, long after the popcorn has been munched, is often attributable to the construction of sound.

The construction of sound is constantly in flux. The room tone captured in one room on the film set, can be completely different than the tone in another room on the same set. Not even the sound recorded on location, from the boom overhead, lavalier connected to the actor, or camera microphone is permanently set, and must be synched in post-production. As I focused on the construction of sound in film, as an indicator of monstrosity, I was surprised to discover three other films, whose plot crept up on the topic of sound *itself*. By this I mean, the filmmaking focused on sound, and the film's

plot also focused on sound. The three films I am speaking of are: *The Conversation* (Coppola, 1974), *Blow Out* (Litto, 1981), and *Berberian Sound Studio* (Page, 2012).

In *The Conversation* (Coppola, 1974) and *Blow Out* (Litto, 1981), the presence of the monster was revealed in the films' sound recording. In *Berberian Sound Studio* (Page, 2012), the context was on sound effects within a film production. In each of these films however, the analysis of sound was a critical part of the role of the main character. What ties *The Conversation* (Coppola, 1974) and *Blow Out* (Litto, 1981) together is not just one specific visual signifier, but instead, the film sounds that signify the presence of the monster.

Context also gives particular sound their sense of monstrosity. Whether it is the audible thumping of a heartbeat in fear, a low animal growl, or the blast of loud drums, sonically the filmmaker prepares the audience for the monster. Composer Irwin Bazelon (1975) ventured that music that had “dissonance—harsh, controversial, disconcerting sounds [equated with] a negative factor implying neurosis, evil, agony, and pain, the opposite of good and right, sweetness and light” (p. 88). John McCabe (1974) emphasized that the quality of *inhuman iciness* can be achieved through the sound of a viola melody. Where would the film *Jaws* (Zanuck & Brown, 1975) be without its melodic leaps, and dark, repetitive musical signifiers to accompany the shark attacks?

In the classic film, *Frankenstein* (Laemmle, 1931), what marked the scariness of the concocted monster was not solely his grotesque appearance. It was not solely the thunderstorm outside, although these elements certainly enhanced the scare factor. It also was not the crackling sound of electricity. The construction of monstrousness began the

moment Frankenstein grunted out a sound. That sound is the moment that created a visceral reaction from the audience. Though his first sounds were hard to discern, the unfailingly eeriness of the guttural sound did its job. Movie audiences were frightened, and being frightened is at the crux of horror. But how is this accomplished?

To find some answers, I examined many sources, including the heavy Hungarian voice of Dracula. Few can deny the hubris and scariness of Lugosi's voice when he uttered the words, *I am Drakuhlah*. Ahhh, the monster speaks! Sonically, the Dracula monster had introduced his Otherness to the audience, both in the resonance and volume of his voice. Sadly, though few like to admit this, Dracula's Otherness was also revealed through the sound of his thick, Hungarian accent.

Embodied sounds, like that of Dracula, are hair-raising enough. It is bad enough when monstrosity is easily discerned or even looked at, but sound can be even more frightening when the source is hidden from view. Sounds where the audience cannot locate the actual source become *disembodied*. That is, when the imagination takes over, and simultaneously, when the audience begins to squirm. This is true whether the sound is disembodied screaming or footsteps behind your back that take you by surprise. *Shhhh*—*did you hear that?* Every sound, whether loud and foreboding, or simple repetitive chords played at low volume, have meaning in the eerie atmosphere of horror.

If the filmmaker has done her job, the presence of the monster moves its very existence out of the viewers' imagination, and sinks its fangs deep into their being. With the sound of disembodied whispers and groans, the desired hair-raising effect in creating

a thriller/horror is in the anticipation that the monster is creeping up beside the viewer, or at least sitting close by them somewhere in the dark.

As I examined monstrosity, in terms of its musical orientation, I realized that we deem human bodies and music as monstrous when they are discordant. When people do not fit in, when they are distant, detached, forbidding, or when they clash with others, they are Othered, and therefore, viewed as monstrous. The same can be said for sounds and music. Sounds and music that are not in tune with the norm are monstrous. Sounds and music that are distant, detached, forbidding, or when they have clashing dissonance, are monstrous. The same goes for sounds and music that use inharmonious chords. Link (2009) suggests, “Monstrosity resides in denying musical orientation toward the categorically complete human body... In short, like the monster, the music of the monstrous derives from its difficulty to apprehend with conceptual clarity” (p. 43).

Music scholar Anahid Kassabian (2001) reasons, “we learn through exposure what a given tempo, series of notes, key time signatures, rhythm, volume, and orchestration are meant to signify” (p. 23). The swell of music can boost an emotional reaction. Hard acid rock can make us feel agitated. Even those who view composers like Wagner and Tchaikovsky as against their personal music sensibilities will allow those classics as an acceptable work of horror.

Previously in this chapter, I described a terrifying film performance from *The Shining* (Kubrick, 1980), where a young boy on a tricycle encountered two twin girls at the end of a long corridor. The writing in the script is flawless. The boy’s fear is apparent. The scene is shot beautifully. However, what adds to the disorienting monstrousness of



the scene is the manipulation of horror-filled music. In this case, the scene included trombone and tuba sections of Polish composer Krzysztof Penderecki's *De Natura Sonoris No. 1* (Penderecki, 1967). In another scene from *The Shining* (Kubrick, 1980), over the tension-filled moments of Jack Torrance's '*Here's Johnny!*' descent into madness, the atonal music of composers *Béla Bartók*, *György Ligeti*, and Krzysztof Penderecki (Donnelly, 2005, pp. 44-51) ushered in the monster. For me, that music was so very much the star of the show, that whenever I hear it, I am transported back to the film. Barrett and Freeman (1989) report on Darwin's views, "Music arouses in us various emotions, but not the more terrible ones of horror, fear, rage, etc." (p. 594). It is pretty clear, from these assertions that Darwin never sat through a horror flick. In that genre, music not only can arouse emotions of horror and fear, but oftentimes, that is its very role.

Chiefly, my sound and music as monstrosity approach pays close attention to the taken-for-granted monstrous sounds, against the visuals of the thriller/horror film experience. In so doing, I look to sound as a sensorial experience that incorporates my filmmakers' hat.

The haunting presence of Mike Oldfield's music, "Tubular Bells," used by William Friedkin in the fright-fest classic, *The Exorcist* (Blatty, 1973), is so recognizably creepy, that the music is stuck to the story of the pea soup-spewing girl's demonic possession. If you have ever seen the film, the iconic music is such an earworm that it alone can make one shudder and take you immediately back to the film.

Another example of music as monstrosity is the way the song, *Stuck in the Middle With You* (Rafferty & Egan, 1973), adds another dimension to Mr. Blonde's torture scene in *Reservoir Dogs* (Bender, 1992). Also, while many people may not independently know the name Bernard Herrmann, most would identify with the staccato strings and sounds he created as a dark musical component for the brutal stabbing scene in the classic horror, *Psycho* (Hitchcock, 1960). Similarly, the repetitive melody of John Carpenter's original *Halloween* (Carpenter & Hill, 1978) had a disturbing and easily recognizable score associated with the film.

Monstrous music and sounds have successfully created keep-the-lights-on moments in many films. From the creepy synths used in *Halloween* (Carpenter & Hill, 1978), to the gothic rock used in *The Return of the Living Dead* (Fox & Henderson, 1985), to even the twisted 1995 hip hop remix, *I Got 5 on It* (Marshall, 1995), featuring Michael Marshall, by Luniz and played in the thriller, *Us* (Blum et al., 2019). In fact, in the films' theme song, *I Got 5 on It* (Marshall, 1995), the tempo of the notes were slowed up. This created a creepiness the original song did not have. Jordan Peele (2018) spoke about the selection of the song not just for its haunted throwback qualities, but because, "the beat in that song has this inherent cryptic energy, almost reminiscent of the *Nightmare on Elm Street* (Shaye, 1984) soundtrack" (Sinha-Roy, 2018). Any film that calls to mind the otherworldliness of *Nightmare on Elm Street* (Shaye, 1984), in my view, can categorically be defined as monstrous.

I was so inspired by Jordan Peele, that in *The Colored Pill* I sonically illustrated the otherworldly with a looped medley of whispers, screams, and night time bugs. I also

morphed the sounds of animal growls and snarls into the scenes, knowing that in scary films, animal sounds typically indicate the other. With this in mind, I used animalistic sounds to enliven my scenes. By sustaining a monstrous medley of sounds, along with the visual appearance of the actual monster/ghosts, I created a constant, tension-building reminder for the viewer, of the close proximity of the monster.

In a film that embodies monsters, such as *The Colored Pill*, the sound of the monster also unlocks its power. At the same time, the sound *is* the monster. Sound can share the same traits of the visuals. Just as the actors can create feelings, the sound can create, as well. The sound *is* the feeling. For that reason, audiences *feel* the screams. In so doing, sound has both the power to reflect, as well as the power to become a part of.

Cohen (2000) shares, “Without music, images seem prosaic, mundane, even lifeless; with music, however, the world of film comes alive” (p. 341). All in all, sound functions as monstrosity by *being* the monster. When well-constructed, sound fills the body with the kind of terror that seeps into the bones. Once inside the body, or the mind, sound *is* the terror.

Regardless of our obsession with visuals, as film viewers, we have been conditioned toward certain sounds, and consequently, we know how to associate the monstrous to horror films. In so doing, film scholar K.J. Donnelly (2005) explains that music has the ability to “*embody* horror” (p. 106). As I explored sound and music as monstrosity, I came to realize there are some sounds that are so monstrous, that even just the hint of them invites terror. This is not a figment of our imagination. Just the mere act of focusing the audience’s attention on particular sounds, can create a tension-filled

emotion. For example, the sound of screams causes tension. The slamming of a door, though not scary, is monstrous in that it causes alarm. The creak of a door raises the hairs on our arms. Whispers can disrupt. Even certain sounds of laughter are instantly read as monstrous. The meanings of these sounds blend seamlessly into our psyche, and are on the par with the frightfulness of a full-orbed moon, a haunted house, or decaying vines dangling down a wall in a horror flick.

The sounds of monstrosity in film include the wind gusts, the low rumble of thunder or the six-shooter that fires. It is the bullet thudding, and the echo that shatters the silence. Monstrous sounds include the echoed footsteps approaching in the alley, the water dripping, the glass breaking, and the knock on the door. These sounds, and so many others, orient the audience to a scary ambiance, and often to the arrival of the monster. Even the very soft sounds in a film can be monstrous. For example, what if the script calls for a penetrating wound? At first glance, one may think that a wound is not sonic, however, consider the splat sound heard in horror films, of blood dripping down from meat hooks. The quality of this somewhat soft sound is monstrous.

Another monstrous sound used in horror films, is the ominous sound of wind. In horror, wind symbolically signals that a storm is coming. As a filmmaker, I am constantly looking for ways to create an emotive intensity, so the sound of a storm or wind is a very effective tool for me to use to raise emotion. Whittington (2007) notes, “The ambient sounds of wind are also connected to the alien or ‘other,’ which is often coded as a threat to humanity” (p. 138). This layered meanings and coding of the other was perfect for the monster-ghosts used in my film. For these reasons, I repeatedly manipulated the ambient

volume of wind and the creak of wind through trees in several scenes. Many times, for an added scare, I lowered the sound to near silence. In this next section, I explore film silence as monstrosity. In the praxis of performance silence, and even stillness, are often meaning-making tools. Lorde (1984) asserts, “In the transformation of silence into language and action, it is vitally necessary for each one of us to establish or examine her function in that transformation and to recognize her role as vital within that transformation” (p. 43).

Often associated with films of suspense, silence and stillness are particularly inventive ways to project horror in scenes. I am reminded of the film character, Dr. Hannibal Lecter, from the psychological horror, *The Silence of the Lambs* (Utt, Saxon, & Bozman, 1991). Dr. Lecter conjured up utterly still calmness to such a height as to project an eerie sense of self-control, which upped suspenseful moments in the film. Clearly, moments of silence can communicate in films, just as profoundly as dialogue, noises, or special effects.

### **Film Silence as Monstrosity**

Sitting barefoot on the side of a river, one might think the night-calling chorus of katydids, frogs, and crickets are a loud bunch, and they are, but even they have a season when their sounds fall silent. The same can be said for film. In the world of film, the sheer volume of sound can be deafening. We have all endured film sounds of roaring dinosaurs, Vader’s asthmatic breathing, or bombs blasting so loud they would put a rock concert to shame. As though that were not enough, all of this can be magnified by added sound design like enhanced and pulsing chainsaws, whirling helicopter blades, and

emergency sirens, all of which are so ear-shattering that even a single moment of volume decrease feels refreshingly like—*ahhh, silence*.

Yet, it is often the boundaries *between* sound and silence that compel the audience to pay attention. The monstrosity in music and sound is not always easily identified in film, because these elements do not always point to unusual or unpleasant sounds. The visuals may be frightful. The sounds may be scary, but the space between the visuals and the sounds—the silence—that, too, can be quite unsettling. Sometimes, the *homo monstrous* monster announces itself with a set of quiet tones, or even with moments of near silence. In so doing, silence, or sounds that lull, can also signal the monstrous.

While admittedly, the cinematography was breathtakingly on point, the omission of sound and the use of silence were the unnerving elements used in the 2018 horror film, *A Quiet Place* (Bay, Form, & Fuller, 2018). In this film, the means of survival for the Abbott family meant living in silence. Here, the element of silence was such a pronounced enhancement that the suspension of sound acted as a separate character. Of course, there was a bloodthirsty film monster present, but there were no ghosts, no razored gloves, no scissors, and no bloody meat hooks, and yet, the silence in this performance was hair-raising. James (2019) reports that supervising sound editor for *A Quiet Place*, Ethan Van der Ryn (2019) stated: “Most people think it’s about how much sound you can put into a movie, but in ‘A Quiet Place’ it was the opposite. It was about how much we could take out” (p. 23). Also monstrous, the connection to death was present in nearly every scene. Along with the amplified natural sounds, what made the film terrifying was the way the filmmakers sprinkled in life events where there was

absolutely no way silence could be maintained. *A Quiet Place* (Bay et al., 2018) is not the only recent film to use silence to create tension. Filmmakers in *A Star Is Born* (Gerber, Peters, Cooper, Phillips, & Taylor, 2018) skillfully employed near silence to indicate the tinnitus condition experienced by main character, Jackson Maine (played by Bradley Cooper).

Within this chapter, I have discussed monstrosity in terms of film sounds and music. I have provided examples from my research film, *The Colored Pill*. I have also provided numerous examples from popular films.

In Chapter five, I continue my exploration of monstrosity by creating a behind the scenes look at the making of *The Colored Pill*. Chapter five describes many filmmaking tips of the trade I employed during production. This chapter also describes an unusual scene analysis technique I adopted, which I will explain further within the chapter.

## Chapter Five. Bone Chilling: *The Colored Pill Behind the Scenes*

*“Every period has its ghosts (and we have ours)”* (Derrida, 1994, p. 241).

*“A story is not a story until it changes. Indeed, until it changes or until it changes someone else, until it becomes a part of the vital histories of change it recounts”* (Pollock, 2006, p. 93).

Bausch (2004) reports, that the late director Sydney Lumet (1996) once said, “Making a movie has always been about telling a story” (p. 138). I could not agree more. As a filmmaker, there is nothing like a great story. *Once upon a time*. Story is where everything starts. *In the beginning*. Story is where consciousness is raised. *There once was*. Story is where awareness is raised. *In a faraway land*. To study whether or not a specific film performance could provide the kind of information that raises awareness, I needed to first just tell a story. So, I did. I told a story about a movement, away from producing pharmaceuticals for all people, to a strategy based on race. In other words, I told a story that identified the effects of pharmaceuticals, purely at a genomic level, but I knew that sounded like the story of pharmacogenomics (because that identification *is* the definition of pharmacogenomics), and I knew that would come across to viewers as medical mumble jumble, just as it once did to me. So, I decided to just tell a story about underexplored aspects of race and health, and in so doing, I disturbed those existing stories. I disturbed existing historical stories that I am already situated into. Like it, or



not, I am situated into a story in semi-darkness. I was perplexed by the story. I was even somewhat afraid of it and so, it captured me.

Whether we are telling ghoulish stories over a campfire, listening at the feet of someone we love, or gripping the velvety arms of a theater chair, nothing compares to stories to capture our attention, scare us, amaze us, and nudge our belief systems, if only just a smidge.

In recent years researchers have argued that storytelling is particularly effective for minority populations. Racial/ethnic communities have a rich tradition of storytelling (Houston et al., 2011; Larkey & Hecht, 2010; McQueen, Kreuter, Kalesan, & Alcaraz, 2011; Robillard & Larkey, 2009; Unger, Cabassa, Molina, Contreras, & Baron, 2012). As a member of the African American community, where bodies of color and narratives, are situated in oral history, I drew on storytelling in film performance. It is through this context I argue that film performance can be utilized as both a theoretical and methodological tool.

For this study, I entered an arena of debate, calling into question the methodological use of film to represent the past, while at the same time; I present a film performance that offers a new paradigm on pharmacogenomics through the pharmaceutical known as BiDil®. Insert a nervous laugh here, as I impress upon the fact that the very communities of color my film targets, know very little about BiDil® or racialized health, for that matter.

Growing up, I remember hearing bits and pieces about Blacks being used as medical specimens, but having learned how to stay out of *grown folks business* early on, I

did not ask questions. I imagine I went back to watching *Frankenstein* (Laemmle, 1931)—a horror I could handle. I did not come to fully understand the snippets I overheard as a child to be discussions about racialized health in general, and specifically about the Tuskegee Study of Untreated Syphilis in the Negro Male (aka Tuskegee Syphilis Experiment) until I became an adult. It was several years from even that point that I learned Tuskegee’s ultimate purpose was not just to watch untreated syphilis, but rather to document the presumption that syphilis was a different disease in Blacks (Jones, 1993).



Figure 1. BiDil Pharmaceutical Label

Fast forward to my doctorate work, when I ran across a pharmaceutical label, presented in Figure 1 below, and several biomedical articles about a medicine with a race specific indication. The new medicine was a combination of two older heart failure medicines, but what spurred my interest further was the fact that the Frankensteinian pharmaceutical had been approved solely for African Americans. For me, the drug BiDil® smacked of the same *bad blood* lineage and pseudo-science of Tuskegee’s untreated syphilis experiment. I was even more confused when I overlaid results of the

HGP (gene map) which reveals that regardless of race or ethnicity, at the level of our DNA sequence, all people are more than 99.9% identical.

Though I did not suffer from heart failure, I felt unusually drawn to BiDil®, even while I was taken aback by it. Maybe it was BiDil's purpose to document a presumption that heart failure was a different disease in Blacks that captured me. Maybe it was thinking that a people who need a separate drug based on their race means that race influences health that would not let me loose. Maybe it was my belief that health is affected by assumptions about race, that broke into my curiosity. Whatever the reason, the intertwining of race and health, illustrated by BiDil®, inspired me and ultimately, formed the basis for my film performance. Indeed, the tale of BiDil® stimulated my storytelling drive, and drive it did. As I delved into the research, I was driven by tales of other race specific drugs. Race specific drugs are like the spin of an eerie, tilted roulette wheel. In this way, we place bets on a very slim possibility of the little white ball actually landing on the colorful pocket of health efficacy, bouncing from: odd number, then even; odd, and then even, until the dealer announces, *no more bets*, and the whole process loses momentum. Only, in the case of BiDil®, there is no one to sweep away the losing bets, and there is no announcement. Instead, the little white ball of race specific drugs keeps spinning and spinning, looking for a new time and place to land.

As much as I saw the approval of race specific drugs as adding to the biologization of race, the arousal I felt for BiDil® became the inspirational spark for my study. The drug haunted my imagination. As a storyteller, I knew there was another side to the story of BiDil® to be explored. Though the drug was approved in 2005, it is even

more relevant today under new management, as we stand at the precipice of personalized medicines—the leveraging of genetic markers to sequence individual genomes to create tailor made pharmaceuticals. In other words, we are not far from the expensive process of creating a pharmaceutical based on the personal Rubik’s Cube of our known genetic markers for disease, and individual reactions to drug remedies.

While personalized medicine focuses on individualism, the social practices of racialized medicines have actually led to less individualism. Mucking up the concept of racialized medicine is the belief that if one person is different because of their race, that somehow means their entire race is the same. This would mean there is no genetic diversity within a race of people. This pernicious terrain, which covers race based medicines like BiDil®, could not be more false. Along with the falsity, in a clean landscape, the hoof prints of racism for this thinking are also visible.



Figure 2. *The Colored Pill* Movie Poster

*The Colored Pill* (film poster is presented in Figure 2) is a medium to educate viewers about the intersectionality of race, racism, and the subterranean vault of history.

This study lays the groundwork upon which other passionate thinkers and film performance scholars can raise awareness of movie audiences as it relates to race and health. “*Tell someone I’m here*” (Galeano, 1992, p. 72). What is at issue in this study, just as it was for the young boy in the introduction to this study who begged to be heard, is the woeful expression of pain and suffering. In this study, it is the personal expression of race as a site of pain and suffering. “*I am here in the world among you*” (Madison, 1998, p. (Madison, 1998, p. 173). That said, I navigated the waters of this study to have a very personal conversation. My purpose was to have a race-focused conversation that could build relationships. In a dual function, the purpose of this study is to take my viewers on a kind of ghost tour. A hunting of ghosts, if you will. Most are familiar with Hollywood ghosts who haunt scary houses or crouch down behind gravestones, but what about the ghosts who still have the chops to do a good work? For this study, I sought those ghosts who are willing to speak the truth about a monstrous history long since forgotten. At the end of the day, my purpose was to build relationships between the history of the past and what Foucault (2003) would think of as *histories of the present*. I do this through the simple-ness of story. Only my focus was not to hover on the periphery of just one story, but instead to piece together many stories, tumultuous stories, all of which juxtaposed with a harrowing history.

The goals that underpin my study are consciousness and awareness-raising, as well as knowledge enhancement about invisible historical incidents. In so doing, my film is not just educational, it is a call to communities of color, and other populations, to responsibly pay attention to the progression of racialized medicines and any other

instance of genetic sameness. I see my job as not only to juxtapose history and horror, but to also offer innovative guidance for other film performance scholars haunted by history.

Arguably, the artistry of film is a salient example of the way important contributions to history are made visible. As such, film performances are powerful communication tools. Theoretically, this research project adds to the development of performance through the critical investigation of a history filmmaking study. Merrill (2006) states, “Performance history ... like other forms of historicizing, involves the performative act of telling a story—literally calling it into being” (p. 65).

It is no surprise that much of the historical legacy of African Americans’ terror-filled history includes marginalization, subjugation, enslavement, and exclusion. In this study, I transported my viewers, in a viscerally compelling experience of history, and led them to experience the repercussions of lived experiences of the past. Everett (2005) asserts, “It has often been stated that history is less concerned with an accurate accounting of the past events than it is with providing a framework from which to apprehend the future” (p. 865). Communities of color, survivors of racial cataclysm, continue to fight for a destiny untouched by race. I believe it will happen. I must believe it will happen, or I might as well not get out of bed each morning.

As a filmmaker, I have watched quite a number of historical films. If American history had been captured on a rare vintage film, extracted from heavy, metallic canister containers, the brilliant translucent flickers of light and then dark from the filmstrip would not only describe the projected newsreel of images, it would also describe an accepted version of history. I can imagine it now. After nestling in our chairs with a box

of buttered popcorn, we would first see the title panel, followed by the sputtering of grainy footage.

First on the newsreel might be the pomp and circumstance of President William McKinley's inauguration. Then the film would cough and fade to black before correcting itself over blaring trumpets. We might see the 1910 fight between Jack Johnson and James Jeffries and then, just before the film goes off its track, we might see a famous actress stepping down from a train. The screen would fade to black, before a long tracking shot of soldiers marching in formation might appear, and we might hear a commentator, with his fake-British accent and voice lacking in emotion, informing all Americans that we have entered into war. Once again, the film would fade to black, but only for a moment before lively orchestral music rises up. Then, we might cut to the fireside chats of Franklin Roosevelt. We would fade to black once more, and then see footage of the Hindenburg explosion. Fade to black, and *ahhh*, there is the moon landing!

These scenes of historical images—a cocktail of light and dark—that might appear and then disappear across the silver screen, come to symbolize what we believe to be important events to our nation, and they are indeed important. Yet, for every flicker of importance placed on images of June Cleaver, decked out in pearls and heels, bending down to a mouth-watering roast in her oven, there is also a great unimportance placed on the uniformed maids of color who trudged to the back of a bland bus after working in someone else's kitchen. As a society, we should be just as committed to those dissolving transitions of our collective history, but instead, most Americans are like the husband who is dedicated to his wife, but only when he is with his wife. The dedication does not

happen often enough. The same can be said about our collective commitment to incorporating all parts of our history.

In a metaphorical but also in a narrative sense, the fade-to-black sequences I studied were the connections between the end of one history, and the telling of another. Like an object from a becloaked magician, the history of one community is shown, while the history of another is swallowed up, and transforms into an old coin that is much more palatable than the truth.

In this chapter, I elaborate on the truth. I elaborate on not just the truth of history, but the truth in reenacting history. In this chapter, I analyze and share some of the thought processes and specific filmmaking methods I used to reach my goal for this study. First, I would like to share the plot and timeline related to making *The Colored Pill*. The log line, listed on the IMDB web site for *The Colored Pill* reads: In a last-ditch effort to confront a lifetime of orchestrating racialized experiments, a miserable immortal heads to a secluded barn where he collides with a vengeful presence.

The storyline for my 70-minute film takes place in Denver metropolitan area where an immortal, tormented with concern over the things he has done, pleads to stay alive. The main character, an immortal I call Bias, has recently discovered plans to be killed because he failed to get a new race based pharmaceutical approved. Why was the drug approval so important? Because a racialized pharmaceutical will allow the immortal to spread more bias in the world, this time, through health. The immortal's chickens come home to roost when victims of his past, come back to haunt him. The overarching



question in the film is whether or not the immortal will be able to outrun his past.

Paradoxically, that is the same overarching question related to racialized medicines.

The film took an inordinate amount of time and effort to produce. First, I needed 1-1/2 years for the pre-production process. When I completed my dissertation proposal, I did not have a film script in hand. I needed to deeply investigate all aspects of the story before a coherent script could even be developed. The research and development portion of pre-production was particularly important because the film was based on historical events. Researching the real-life events took a great deal of time. By the time I was at the point of writing a script, (actually five scripts), I needed to raise enough money to shoot the film, and produce a solid shooting script—the script from which a shot list could be created. At pre-production, I also needed to purchase stock footage, work with talent agents to hire actors, rent a large meeting room at a local hotel, host casting calls for main actors and extra roles, begin location scouting, negotiate all contracts including a contract for insurance, schedule the cinematography and drone operators, hire additional crew, as well as hiring makeup/special effects professionals, etc. With careful planning, the production aspect of filmmaking, including re-shoots, only took a few months.

Though the actual production element went by relatively quickly, the issues and delays related to post-production work were seemingly *orchestral*. In the end, the post-production work took well over two years of near daily hands-on work.

In addition to editing, the post-production process included Foley and sound effects/design, music clearances, the creation of a film trailer, and making all visual effects decisions. I cannot forget that the post-production process also included color

correction work, opening/ending credit creation, as well as the creation of a film poster.

There were numerous, unforeseen hurdles to be overcome in post-production.

Additionally, there were numerous, unforeseen costs.

After the post-production process, the film was ready to be analyzed. Many film performance scholars analyze the making of their films in terms of pre-production aspects. This kind of analysis might include interrogation of everything that took place during pre-production and production. While I performed each and every one of the pre- and production tasks, I will not analyze the making of my film from those aspects.

Other film performance scholars analyze the making of their films strictly in terms of its post-production components. Though I performed each of the post-production tasks, briefly outlined above, I will not analyze the making of my film from those aspects either.

Some filmmakers analyze the business side of filmmaking, studying corporate financing, crowdfunding promotion, and even distribution deals. Others examine their film through an analysis of the music support, including not just the selection of music, but questions about the timing of specific music queues. Additional film analysis could include an examination of the cinematography alone, answering questions about the uniqueness of the shots or how color and lighting affected the overall tone conveyed in the film. Others analyze just the special effects, or just the editing, or even just the dialogue choices.

Suffice it to say that each and every one of the above mentioned filmmaking elements was covered, by me, in the making of *The Colored Pill*. As temptingly easy as it

might have been to analyze and describe my film in one of these myriad of ways, I have chosen another route for analysis. The route I chose is based on readings from one of my favorite newspapers, *The New York Times*.

Years ago, *The New York Times* created a video series, whereby film directors could share scenes from their recent films, by focusing attention on actual scenes. They describe the scene, including the myriad of decisions made. Sometimes the directors describe the film based on their personal motivations. This wonderful catalogue of filmmaker decisions is called *Anatomy of a Scene*. It skillfully illustrates the many thoughts and behind-the-scenes decisions and techniques made by filmmakers.

In keeping with the vein of *The New York Times Anatomy of a Scene*, in this chapter, I deconstruct *The Colored Pill*. All throughout this chapter, I essentially slow down the film so I can deconstruct and interpret it in general, while also stopping to explain six pivotal scenes. Before I recreate a more formal Anatomy of Scenes (saved for last), I share a fuller description of the film, including my research question for this study. I discuss the process of structuring my narrative, incorporating instrumental tools to every filmmaker such as the thoughts behind important elements of sound design and Foley. I also share some of the challenges I faced. I begin this work by providing a contextual analysis of my film. Here, I provide an important backdrop for my thinking about the film.

### **Contextual Analysis**

Putting aside the success of paranormal television shows like *Ghost Hunters* (Pilgion, 2015), films like *Paranormal Activity* (Peli, 2009), or *The Conjuring* (DeRosa-

Grund, Safran, & Cowan, 2013), many people do not go out of their way to capture or report about hauntings—spirits who have returned to take revenge on their oppressors. As opposed to revenge, most of our everyday lives are in search of meaningful relationships that nourish our spirit, and feed our soul.

In the making of *The Colored Pill* film I experienced parallel elements—the nourishing of my spirit and the feeding of my creative soul, while going out of my way to capture the supernatural in terms of ghosts, or what I call monster/ghosts. By introducing the supernatural, somehow the natural became easier for me to explain. It became easier to understand the consequences of violence inflicted on one of my female characters, once she became dispossessed. Like other monsters in history, the African American has often served as the whipping boy for man’s monstrosity. But, what about the African American women?

In this film, the bonds of history are boldly exposed through the transformation of my film characters—now ghostly victims of racial experiments like those conducted at Holmesburg Prison. In the process of these victims’ reclamation of their past, audience members are reminded that their appearances signify consequences of past acts on the present. Kröger and Anderson (2013) share, “When ethnic identity and unity are threatened, ghosts appear as reminders of a shared cultural past” (p. xi). The ghosts in *The Colored Pill* push for recognition because they hold the memories—our cultural memories. In my film, they represent ghostly reminders of our shared history of marginalizing Others—in this case, vulnerable outcasts of color.

In the film, the ghosts are angry (are movie ghosts ever not angry?). The presence of their angry bodies tells the audience that something is not quite right with the history. Their anger makes it known to the audience that a wrong has been done to them. It makes know that something has been taken from them—something they can never get back; hence their desire, in my film, for revenge.

The inception of *The Colored Pill* film was not pitted in some subterranean interest in horror. Instead, the story of race based medicines seemed to me to be a type of ghost story—an old thing lodged in the canal of history. An old thing stuck in both our recent and distant history until the distinctions between the past and present are hopelessly blurred. Given those givens, it seemed to me that behaviors I view as the most archaic and dangerous often seem to dwell within the tender cavities of practices based on the color of skin. So dangerous are practices based on false human hierarchies rooted in physical characteristics, that I see them as a horror. Hence, I created a horror film.

My selection of the horror genre was predicated on my desire to showcase not just ghosts, but monsters. When I use the word *monster*, gothic images of grotesque gargoyles or medieval blood-slurping beings may bloom in the mind, however the etymology of the word lingers from the Latin root *monere* meaning to warn, and the noun *monstrum* meaning evil omen. By these definitions, I knew that by using monsters in my film, I would be able to *warn* my audience viewers, as a kind of omen about the hazards our society might face if we continue to reify race with racialized medicines.

In *The Colored Pill*, I show social hazards through the performance of fear. During a flashback sequence, one of my female characters shows abject terror in the way

her body, targeted for racial violence and experimentation, is forced down onto a bloody table. Adding to that performance are human monsters showing themselves as physicians, hunched over her black body while she thrashes against their hands in panic. Williams (1995) describes scenes like this one as, “the spectacle of a body caught in the grips of intense sensation or emotion” (pp. 142-143). So physically exhausting was this scene for my performer playing the role of Anarcha that her scream had to be dubbed in during post-production editing. The actor was just too physically spent for the type of screaming audiences would expect in a scene such as this one.

Later in the film, viewers see an empowered Anarcha, as a ghost/monster, transformed from the socially disempowered girl on a bloody table. In her transformation, she is revealed as an empowered person, albeit with her own monstrous and tyrannical behaviors. Contextually, this performance was critical to the film in transforming victimhood into something other than passive behaviors. Further, in terms of the historical background of horror, I did not want to fall into a stereotypical fate where monsters are defeated by human forces. If I had allowed that, my monster/ghosts would have fallen into the unenviable position of being both visible in life, and invisible in death.

I am invisible, understand, simply because people refuse to see me. Like the bodiless heads you see sometimes in circus sideshows, it is as though I have been surrounded by mirrors of hard, distorting glass. When they approach me they see only my surroundings, themselves or figments of their imagination, indeed, everything and anything except me. (Ellison, 1952, Prologue)

For reasons of both invisibility and visibility, past and present, and so much more, *The Colored Pill* did not end up being easy entertainment. It is not an easy movie to watch. It

is not a neat-and-tidy topic, because the horrible things depicted in the film, actually took place. Oppressing people based on differences is not just about our past; it is about our present. I brought these occurrences into view. I knew I would do that, going in. I entertained people in a particular way—a way that made people begin to think about the world we live, and of course to think about what decisions have to be made to create the kind of world we all envision.

With that, I dived in head first into history. I stepped squarely and forthrightly, into that space of story and connected the dots on the things that have happened in our country. My curiosity had already opened the door. I just walked through it but in doing so, I drew lines from the history to the present. My work is situated in the field of history, but also squarely in the field of intercultural communication with a solid emphasis on race, performance, and monstrosity. Cohen (1996) asks, “Perhaps it is time to ask the question that always arises when the monster is discussed seriously ... Do monsters really exist? Surely they must, for if they do not, how could we” (p. 20)?

I could not agree more with Cohen’s implied assessment of the monster. Our monsters are, well, *ours*. They are our fears; our apprehensions, our buried desires, and whether we believe or disbelieve, monsters are us. That is why we cannot get enough of them at the cinema. That is also why I use monsters as a theoretical construct to learn more about how a film performance, full of monsters, can affect knowledge. Mittman (2012), who studies monsters in art and legend suggests, “Monsters do a great deal of cultural work, but they do not do it *nice*ly” (p. 1). In keeping with Mittman’s views, *The Colored Pill* is not a *nice* film. It has a historical-cultural trauma bent, which depicts

things that are not necessarily *nice*. It contributes to the conservation of history's cultural artifacts. In fact, highlighting the social implications of racialized health, the film performance serves as a kind of cultural artifact.

MacDougall (1978) states, "Since all films are cultural artifacts, many can tell us as much about the societies that produced them as about those they purport to describe" (p. 405). Carefully examining the cultural artifacts in a film—the voice and dialogue, the time period of the piece, the shots, the discordant sound/music—each of these artifacts contain vivid clues about the histories being displayed.

Foucault (1972) once called the sifting through human thought processes as the *archaeology of knowledge*. If Foucault's epistemological system of knowledge is so, then the sifting through histories also reveals quite a bit of knowledge about the culture in question, as well as an assemblage of their perceptions about the larger society. With that, it stands to reason that the cultural artifacts in film help us to win the war of historical recognition, by exploring and re-creating what is, and is not, a cultural norm. By examining these boundaries, we take a close look at our current place in the apocalyptic, dystopian, or global world, our fears and anxieties, and in the case of *The Colored Pill*, the communities of color whose health was put at risk simply because of the color of their skin.

In seeing my film performance as a cultural artifact, history as a cultural artifact fell transparently. Many Americans like to think of the history of the United States as a kind of *I-think-I-can, I-think-I-can* rugged individualism where optimism, sheer will, and hard work gained us independence. Our democracy is based on this ideology, but for



some, history is more than just a narrative about an *I-think-I-can* blue train. Rather, history is made up of individual stories, as well as collective ones. For some, individual stories are little more than idealized narratives of the truth, that leave out instances of belittling and Othering. Such is the construction of historical realities for the rarely spoken of victims of racialized medicine and medical treatments. Collecting troubling stories about the racialization of medicine were a critical part of my study.



Figure 3. Filming *Tuskegee Monster/Ghosts*

In filming, I realized that my work in cultural artifacts continued further than I previously believed. On-site photograph of filming is presented in Figure 3. I came to see the costumes from each scene, as cultural artifacts on the time. I came to see my filmmaking tools as types of cultural artifacts to raise awareness. I knew these cultural artifacts would confound the experience of my film performance viewers, as well as alter their knowledge.

I drew support for film performance as a cultural artifact from scholar, Dwight Conquergood, whose work invigorated my own research. Conquergood used

performance as a functional tool to communicate with cultures different than his own. In doing so, he tressed his work to the critical area of cultural artifacts.

In another study in cultural artifacts, Conquergood's (1985) film, *Between Two Worlds*, allowed the audience to experience life among Hmong refugees. The audience could see the violence done to their culture and spiritual beliefs by society.

Conquergood's (1985) *Between Two Worlds* film performance is pertinent to my study, as a part of my research asks focus group participants to view and speak on the negative toll racialized medicine has had on the African American culture.

I synthesized my positionality also in the work of D. Soyini Madison. In her analysis of affirmed and privileged lives and experiences, Madison positions pedagogy of performance as converging with critical engagement. Expanding the performance frame, I believe when Madison (1998) used *poetic transcription* to analyze the oral history of Mrs. Alma Kapper, she connected to cultural artifacts both in the rhythmic performance of her voice and in her narrative. In close reading of the innovative work of D. Soyini Madison, it is clear that she used performance as a way to amplify marginalized voices. The space between both Conquergood and Madison's exemplary work in performance formed the sticky mastic that held together my approach to filmmaking as performance.

As my study expanded, I realized the vast, multifarious process of filmmaking, involves many artifacts. Starting with the demands of research, which ultimately led to a film script, both the research, the script writing software (Final Draft®), and the script itself are post-production artifacts. In this connection, the filmmaking I engaged in was practice-led, in that the research ultimately led to the writing of the script and

subsequently to the film pre- and post-production. An analysis of the film as a cultural artifact also allows me to consider the creative contribution the film makes in terms of its script. In addition to the script creation, at the pre-production stage of filmmaking, the location agreement, head shots, insurance documents, actor contracts, and licensing agreements all are cultural artifacts. These items and more lead up to the actual film production, which has its own artifacts. Camera equipment, boom mics, shot lists, wardrobe changes, archival photographs and footage, production notes, call sheets, props are just a number of artifacts created and managed during production. In post-production, during the editing process, there is a variety of editing software, editing notes/schedules, sound library items that also make up the film's cultural artifacts.

### **Description of Film**

Some have asked why I used the name, *The Colored Pill*, for the film title. A rose by any other name, right? When I named *The Colored Pill*, I knew the term *colored* to describe people of color was as outdated as a duck-and-cover drill. With no disrespect to the National Association for the Advancement of Colored People (NAACP), describing a community as *colored* was outdated. Using the terms Black or Brown are not just physical descriptions of people of color, they are also social designations (categories) that have not truly been answered, at least not in medical communities.

It is somewhat fitting that I became interested in a narrative about a pharmaceutical that includes monsters and ghosts of the past. After all, kissing us on the mouth is the fact that we literally carry our past around within us, encoded in our DNA. Despite our history of the misapplication of sanctioned categories of race, included the

former *one drop* blood rule to define race, the misuse of race continues in health. It certainly continues in the case of BiDil®. By linking the treatment of heart failure to a racialized body (as opposed to other factors such as family history, lifestyle habits, diet, or life experiences), science has eliminated the very real possibility that this population is as genetically diverse as any other population—having been created from a matrix of several ancestral lines. This is pertinent because any one of these ancestral lines may or may not be responsible for heart failure risks in some African Americans.

For me, it seemed we had approved a drug for a race of people, as though we had found the gene for heart failure, and that gene was called *being African American*. Race is a social category, but by approving a drug for a social category, we are treating African Americans as though the very color of their skin is responsible for their illness. In my view, this behavior framed the question of race in biomedicine back to purely biological terms. Hence, the idea of a pill for people of color, turned into a feature film I called, *The Colored Pill*.

“Where do I begin? My story is so much larger than anything I could tell you” (Lakota, 2017). These are the dark lines of dialogue uttered by the character, Bias, near the beginning of *The Colored Pill*. As I mentioned earlier, the film is a story about an immortal, sent here to spread bias in the world. This conventionally coded immortal—with his human-looking face, human clothes, and human voice, walks among humans undetected. My thinking in creating this character was led by questions like; what if bias in the world was a real, breathing entity that we cannot see? What if bias is the reason for all the racism, sexism, and xenophobia in the world? And, what if that biased entity ever

took the form of a human? Would we recognize it, or would it continue to do its terrible job? These were the questions running through my head as I wrote the script. For these reasons, I knew early on, I would name the main character in the script, Bias. I used the word *bias*, both as a character name, and also as a scary metaphor for the unintended, unconscious, or implicit dynamic that exists in the world. Choosing to depict *bias* as a character created a monstrous quality to his visible humanity. In so doing, my plot device was designed to advance a very clear dialectic; that bias in health has aided in the oppression of African Americans.

Adding to the story is the peril the entity, Bias, finds himself in, which involves dialoguing with another immortal about a plan to get out of hot water, to facing his doom in a remotely located barn. It is a not-so-ordinary story about social blindness. It is a story about regret. It is also a symbolic story about bias, and how it may never end if humans do not do something about it.

Into this fictional beginning, based on my thoughts about bias, I folded very real historical events into my script batter to create a new way of comprehending terrifying elements of the past, present, and possibly our future. *The Colored Pill* uses the lives of five American narratives to drive the story. The five narratives are: Dr. J. Marion Sims, Anarcha Westcott, Fannie Lou Hamer, as well as the victims of both the Tuskegee Syphilis and Holmesburg Prison experiments. These are not just a collection of empirical facts, nor does the film attempt to create biographies of the five narratives. The film presents these bodies as powerful sites of discourse. In a search for nonnegotiable authenticity, the film provides new insight on widespread abuses, an often overlooked

part of our history. Through the film, I argue that these incidents—these living horrors—form an important part of racialized health in the United States. With a nod to scholar D. Soyini Madison, the script I wrote *bears witness* to the voices of the ancestors, and to historical events experienced. In the film, I also witness modern-day race specific health treatments as I call to task the drug, BiDil®. In an effort to uncover the monsters of our past, I challenged myself with helping audience viewers to also *bear witness*.

On a performance level, I became a witness to these not-so-distant monsters by retelling their stories. In so doing, the audience carries the fire. By that I mean that by viewing the film, they now carry the knowledge of historical events that have often times, been buried. Emberley (2014) shares, “The role of the *becoming*-witness is that of being subsequently tied to a history of events that may or may not affect one personally, but to which one can no longer remain unaccountable” (p. 7). Similarly, performance scholar D. Soyini Madison (2007) highlighted co-performative witnessing as, “*being there and with*” (p. 829). In producing and directing *The Colored Pill*, I was *being there* and *being with* the actors in what Madison (2007) described as, “feeling, sensing, being, and doing witness” (p. 829). As a witness, I both acknowledged the presence of the ancestors—the dead victims—and saw their claims on a horrific history.

## **Horror**

I have always been a movie buff. I have had an even longer interest in storytelling. As far back as I can remember, I have been writing stories. So, when I told other people that I was writing a social thriller as a part of my study, no one I knew was surprised. When I added that my social thriller would not be a book, but rather would

express society's injustices in a horror film, the most obvious and prolific question was: *What's the film going to be about?* Go figure. The short answer was it was going to be a film about a pharmaceutical. No one was scared. Despite that, BiDil® kept me up at night, just as other horror stories had.

Quite a bit of scholarship about horror focuses on an assemblage of monsters in literature and in film, definitions of the horror genre, or examinations of ideological concepts about horror. However, few delve into the effectiveness of the cold chill of a horror film, not just in terms of its visceral scares, but in the deep abilities of monsters and ghosts to enlighten.



Figure 4. *Filming Monster/Ghosts Uprising*

Lest the revenants—the monster/ghosts in my film are perceived negatively, a distinction should be made that they are *not* demons. *Horrors!* Though fierce in appearance, my monster/ghosts carry the past forward, although admittedly, with an uneasy queasiness. On-site photograph of monster/ghosts is presented in Figure 4 below. French linguistic philosopher Derrida shared, “The cinema is the art of invoking ghosts” (McMullen, 1983). I invoked monster/ghosts to dialogue with viewers about their

afterlife memories—things that have taken place in the past. Though invoked, of course the audience is not engaging in a *real* dialogue with monsters, just as I was not, but I knew that if I artistically surrounded the film with ghosts, the performance would take on a fantasy-like quality.

Even though in the film, the Otherness of the monster/ghosts is made flesh, I knew that my audience would not leave the film with a new fear of these bodies of color. Instead, I designed the film so that they would leave the film at least knowing the instances depicted were true. After all, the film is based on my research. Recall the overarching research question (RQ) that guides my argument is simply: How does a historical film performance function to affect knowledge of race based medicines?

Horror is generally fiction designed to scare your socks off, but I came to write a particular genre of horror—a social thriller—to enlighten. In a previous chapter, I highlighted social thrillers. Suffice it to say, social thrillers tend to ask more questions than provide answers. Whether the social thriller examines gender equality as in *Rosemary's Baby* (Castle, 1968) and *The Stepford Wives* (Rudin, De Line, Scherick, & Grunfeld, 2004); racial inequalities depicted in *Night of the Living Dead* (Streiner & Hardman, 1968) and *Get Out* (McKittrick, Blum, Hamm Jr., & Peele, 2017); or class and race seen in both *Candyman* (Golin, Sighvatsson, & Poul, 1992) and *Guess Who's Coming To Dinner* (Kramer, 1967), filmmaker Jordan Peele shares that social thrillers, "all deal with this human monster, this societal monster. And the villain is us" (Castillo, 2017, para. 1). So enamored have I been with thought-provoking horror and embedded



social critiques that social thrillers provide, I selected this genre for my cinematic language early on.

## **Processes**

One of my favorite quotes about writing is by writer E.L. Doctorow (1988). Doctorow (1988) says that writing is, “like driving a car at night. You never see further than your headlights, but you can make the whole trip that way” (p. 305). Though Doctorow was referencing writing, filmmaking has a similar headlights-in-the-dark experience, or deer-in-the-headlights experience, even in the rosiest of circumstances. Yet, making films fills my soul in a way that is only paled by writing. Writing has always been within easy driving distance for me, but for this study, even that involved a number of U-turns. Though literally a race against time, all in all, the writing, producing, and directing of *The Colored Pill* was an absolutely wonderful experience! It was incredibly rewarding to execute my vision as a narrative-led film. It was incredibly exhilarating to see the words of my script, come to life. It was incredibly exciting to tear around the set—a set I chose and designed. It was incredibly thrilling to bring the jigsaw puzzle of raw footage alive through editing—its own dense thicket. It was all of these things, but if I painted the process like eating from a bowl of sweet cherries, that would be a misimpression. My back was not exactly bent like a palm tree, but it was not straight either. The process of filmmaking was incredibly taxing, not to mention, stressful. There are more moving parts in making a film than it seems, and there were many challenges before anything actually takes place on the screen.

The first time the audience spies the flesh-eating monster/ghosts on screen, there needed to be little possibility of mistaking them for living people. By the same token, their monstrousness needed to come primarily as a result of human actions. For this reason, I was challenged to indicate a connection between the monster/ghosts, and the living (or in this case, immortals). As monstrous beings, my characters exist to terrorize the so-called *normal* thresholds of our world. For me, my monster/ghosts were the literal symbols of past medical horrors.

Literature scholar Paul Budra (1998) suggests, the “threat in postmodern horror ... is not the lurker on the threshold, but the very absence of thresholds” (p. 190). In *The Colored Pill*, I disrupted many film thresholds that are encoded social norms of feminine and masculine. In my film, I challenged myself to depict both female and male monster/ghosts as equally monstrous. One of the ways I met this challenge was through my character, Anarcha. Though she is situated as monstrous, I did not bind her evinced power. Instead, I used her monstrous status to empower her through film sequences in a kind of female-as-hero characterization, displayed through her demonstrable anger and take-charge attitude. This allowed audiences a pleasurable and much-desired subversive read of the film, and one that I hoped would earn their admiration for Anarcha standing up to her oppressor, when she had the chance.

In another challenge, I gave myself a break away from traditional horror. At the end of the film the power is unsettled, and taken away from the main patriarchal figure. At this point of the film, as the monstrous female Anarcha, is no longer the object of

violence, and the power is in her hands. Untraditionally, the power is also squarely in the hands of the other monster/ghosts.

Another challenge I had was in positioning Anarcha as a kind of hero. At the time of her actual birth, physicians were heralded for their 19<sup>th</sup> century medical, albeit experimental accomplishments, like the misogynist and rapacious Dr. James Marion Sims; but who mourns for Anarcha Westcott? My sweet Anarcha continues to wear a veil of invisibility, hardly the garment of a hero. She took her last breath long before *we-the-people*. She was a part of the people who lived and died on a slave farm in Mount Meigs, 15 miles from Montgomery, Alabama. I wondered who mourns her, and then it dawned on me—I do.

In the film, I created an environment where the viewers might also grieve for Anarcha. Bruce (2005) spoke about this when he notes, “classically [ghosts] have scared us ... we have been encouraged more recently ... to grieve for them instead” (p. 23). I see Anarcha as a hero because of her ability to live and survive in a harsh environment, but given her circumstances, the fact that most people do not know Anarcha Westcott is not all that unusual. We have seen this in history.

What is provocative about reflections on President Thomas Jefferson is that few remember, enslaved-until-his-death, Sarah “Sally” Hemings. We do well to remember that, while objectified by social oppressors, Sally Hemings’ life and death had very little value beyond that of economic. The same can be said for Anarcha Westcott.

In filmmaking, I conveyed to my audience that, named by her Otherness, Anarcha was socially ghosted. Author Arthur Frank (2010) reasons, “A life that is not fully

narratable is vulnerable to devaluation” (p. 75). In the case of very much devalued Anarcha, she was legally defined by what she was not: not White, not free, not fully human, not fully female, not equal, and not in possession of dignity or respect. She was placed in the unenviable position of being visible, yet not fully visible. As Ellison (1952) states, “I am invisible, understand, simply because people refuse to see me” (Prologue). Diverging from these tenets of normality, Anarcha was bestowed with a humiliating identity based on the color of her skin, or for the tasks performed by her, Lucy, Betsey and the nine other enslaved women that were owned or leased *guinea-pigs* of Dr. J. Marion Sims. Anarcha’s world-weary body, easily accessed by others in the antebellum era, presented itself to those in dominant positions as worthy only to nurse the babies, plant the vegetables, sweep the floors, cook the meals, dress the sick house wounds, and stoke the fires, all at the pleasure of Dr. Sims, and other like him. Today, there exists only snatches of her existence, and while I told her story, this film was not solely about her. How to balance my love for this woman—my foremother—and the need to tell other stories was no easy feat. She placed her mournful story inside of me, down where I could not forget it. Reverently, I no longer saw her as just a slave girl. I also did not see her as a bag of crushed bones confined in an unmarked grave of coarse rocks and gritty Mississippi gumbo dirt. For me, she was real.

In the end, I decided that showing a rendition of her face, her black body, and speaking her name would honor her. During the actual writing of the script, I was so inspired by Pearl Cleage’s (2006) poem, *We Speak Your Names* (pp. 5-6), because it seemed to encapsulate everything I felt for my character, Anarcha. I must have read the

poem 50 times during the script writing, so its impact can most assuredly be felt in the film characterization of this most important person in history.

We are here to speak your names  
of the way you made for us.  
Because of the prayers you prayed for us.  
We are the ones you conjured up, hoping we  
would have strength enough,  
and discipline enough, and talent enough, and  
nerve enough  
to step into the light when it turned in our  
direction, and just smile awhile.  
We are the ones you hoped would make you  
proud because all of our hard work  
makes all of yours, part of something better, truer,  
deeper.  
(Cleage, 2006)

I spoke her name during the film, but it is important that I reiterate the speaking of her name, Anarcha Westcott. I speak it here, so her name will not be forgotten. I speak it in obligation to the past, and in honor to her. I speak it to reconnect her with a time in history from which she so abruptly left. I speak it in love and deference.

### **Finding My Story Through Research**

As I reflect on the actual process of choosing my story, the first thing I must confess is that the story chose me. For this study, I conducted my research in two ways. First, getting down to brass tacks, I dug through research journals, newspaper articles, books and treasure troves of vintage photographs to uncover factual instances of racialized medicine. In this process, I found information on the irrefutable harm done to civil rights leader Fannie Lou Hamer, and hundreds of other women of color and lesbians who were given the false impression that they had been given appendectomies when, in fact, they were given involuntary hysterectomies. The research showed that medical

ideologies made it possible to use African Americans as human guinea pigs in medicine and in experimentations.

There were times that history revealed such creeping horror that it nearly came across as a low-budget slasher film. I discovered creepy stories of racialized experiments performed on inmates in several prisons. I read about racial experiments performed on military soldiers. Placebos dispensed as medicine in the most gut wrenching circumstances took place. Body parts were put up for auction in some cases. In other cases, bodies were stolen from morgues, all under the guise of scientific experimentations. These and other experiments were made known to me through this my early research.

Much like good detective work, in my early research, I cast a wide net, seeking diverse opinions, perspectives, and thoughts regarding race based medicines. This was not as simple as it might seem, as I had to navigate through huge vats of possibilities for films. In fact, I uncovered so many fascinating aspects of race specific medicine that I was nearly led away from what sparked my interest in the first place.

Dissecting pharmaceuticals as an intersecting discourse on race, and the social construction of identities, was made plain to me through arguments from race scholars. In my research, agendas in race disguised in health were rendered understandable. The birth of America and racial privilege, two elements that fit together like beans and rice, was explained in my research by race scholars like Bernadette Calafell, Patricia Hill Collins, bell hooks, and Kent Ono. I drew inspiration from their radical work, and knew I would apply it to the creation of my film. Race based pharmacogenomics—the health sciences

documentation of racial differences—was laid open and surprisingly revealed its 1950s inaugural study of minorities including African Americans, Africans, and Mediterranean groups.

Unfortunately, in this country, if you differ from the majority—any sort of majority—you will most assuredly face a deluge of discrimination and bias. To that end, I engaged in lengthy research explorations with intercultural scholars, who explained how difference influences cultural perception. In fact, intercultural health scholars revealed for me the structural inequities of healthcare, and the role of culture in health and illness. This was of particular interest to me as I, too, contribute to current health communication scholarship by investigating the varied ways in which the African American culture has been conceptualized in racial applications of health.

Members of the medical community, including physicians, scientists and professionals in bioethics, applied special knowledge to my research as they morally justified their use of race in genetic research. I was taken back by their illustrations because they applied their knowledge while at the same time, acknowledged that racial self-identification is unreliable in negotiating healthcare practices. As I read through their research I wondered, pray tell, what about people who identify with two races? What about those who identify with more than two?

In my research, I was enamored by the probing dialogue of critical theorists, and the way they synthesize relationships between power and health. While fascinating, many of these research products had the ability to take me slightly off topic. For this reason staying the course in my culture-centered approach was an arduous battle.

My second method of research involved moving from *what* to *whom*. This area involved the sharpening of rich storytelling tools. In finding the story within the actual research, I had to choose which historical details would affect the audience the most. I also had to keep an eye on which details would draw the audience into the story, so they would feel as though they were a part of it as it unfolded. While the vast majority of the characters in my film were composites of real people, I still needed to think through how to make the film characters believable and engaging.

### **The Historical Reconstruction**

The historical film reconstruction was so much more than just an act of imagination. Central to the film was the real-life history, drawn from extensive research. My research helped me cobble together the stories of men and women of color whose voices have been silenced, but how was I ever going to contain the bigness of historical events within the smallness of a film? It would stand to reason that the reconstruction of history, with all its lost narratives, shadowy details, fragmented memories and inheritances, is haunted. Eliminating ghosts from the retelling would have been a form of whitewashing the research I had discovered, not to mention would erase the significance of what the monster/ghosts had endured. The master plots of these histories of trauma, loss and death could make evil morticians engage in yellow-toothed smiles.

In terms of the historical reconstruction, I made sure that most of my monster/ghosts remained speechless. I symbolized the voicelessness of these victims, not to re-marginalize them, but to accurately represent that the trauma they endured was so



severe that even as undead, they still could not find their voices. I knew this would symbolize to the audience, the mournful despair of past incidents.

Additionally, I conveyed an eerie symbolic meaning to the unspeaking state of my monster/ghosts. In this double-edged symbol, I recall for the viewers that in many horror films, the mourning of the monster for the life they once held is often so all-encompassing that they are often silent.

### **Writing the Story/Preparing the Shoot**

In storytelling, the subject and the actual story are often not the same. To this end, I had a set of blueprints based on research. I had discovered the subject I wanted to tell, but I needed to either sculpt a story, or investigate what story was already sculpted. In creating this film, I decided to do both.

Telling a true story involved turning all of the factual elements I had uncovered in my formal research, and mold it into a work of art my audience would *feel*. While I was translating and molding the story, I also needed to ensure that my thumb was not on the scale when weighing the truth. How far could I push the art without changing the historical truth? And, what about the human monster, ever present in history's twisted tale? How would I weave his story into a cohesive and entertaining film performance? These are the questions that danced before me as I began to write.

Just as a stethoscope can tell the story of the living by the sound of the heart pumping blood through the aortic valve, the pen tells the story of the dead, through the ink. Being a writer, a nurturer of curiosity, I followed several stages in writing *The Colored Pill* script. I initially wrote the first version of the script fairly quickly. Then I

worked on it a bit more, and a bit more before deciding that version was too big, too clumsy, and too hard to produce. That first version also had too many characters, and was too insufferable to convey in a short time frame. So, I began anew.

Conceptually, in the second version of my script, I disassembled what I liked from the first one. This resulted in a version that was cleaner, and one I felt much more confident about it. Admittedly, in that second version, my writing was more focused on the true stories, instead of on the scare. I wanted the scary aspects to be much more intuitive, rather than a graphic burst of blood and guts. Then again, it was, after all, intended to be a horror film. If I had it to do over again, I would have written the script placing focus on both the story and the horror. The daunting problem with my second script version was the scenes between the main characters. I did not feel those scenes sufficiently captured the inherent tension of race based medicines. While I sweetened the pot many times in that second version, in the end, I was still not happy with it. So, grappling and unsated with the second version of my script, I began again.

Film instructor Alexander Mackendrick (2005) shared, “Screenplays aren’t written. They’re re-written and re-written and re-written” (p. 40). Truer words were never spoken. I had mud wrestled five scripts before the creative process finally turned me loose with the bedrock for a film. It was not until that fifth version that I felt comfortable and had a sense of satisfaction that what I had written was better and clearer than earlier versions. Since I was writing with production costs in mind, at the point of my fifth script, I felt I had created the best, richest script I could champion and produce, given the limitations of my budget.

The narrative arc of the final script was decided well before filming. The narrative arc is, of course, considered at the writing stage, yet as the Director of the film, it was important that I ensure that demonstration of the arc was exhibited in production. The overarching plot point in the film was whether or not Bias' plan to stay alive would be successful. In the beginning of the film, Bias worries his plan to stay alive would not work, but he went through with the plan anyway. The main external conflict this leading character deals with clearly trying to stay alive. This character was also written with an internal conflict. The emotional process the character feels is that internal conflict, exhibited in the following line of dialogue:

*Bias: I've taken full responsibility for everything I've done in the past. [But], I'm not very nice! You can't spend hundreds of years putting bias in the world and still be nice!*

The internal conflict Bias feels is shown (and written) in the way the character wrestles with regret for the bias he has placed on the earth. Complicating the role of Bias further, he positions himself as an anti-racist, White anti-hero. I wrote Bias as stagnant in the script; he is regretful and remorseful, saying, *I've done horrific things*, to discuss the discriminatory and biased behaviors he has inflicted. His anti-racist behaviors could easily be viewed as self-serving, as he has clearly only discovered/atoned for his behaviors once it became clear that his death is imminent. While Bias describes his behavior negatively, his number one goal is to keep himself out of trouble by any means necessary, rather than showing any interest in helping communities of color by stopping the world-wide introduction of a new racialized drug. In doing so, he has re-constituted Whiteness. As a true horror villain, he thinks only of his own mortality. With that, his

atoning dialogue was written to be self-serving. In fact, the script was built so the audience would be led up to the point of conflict with the monster/ghosts. In the end, I made the decision to have the monster/ghosts literally eat the protagonist (Bias) alive. I wrote the consumption of their enemy as a symbol for the monster/ghosts to literally *swallow* their past, and yes, to also be a scary scene for the film.

I must say, I gave this particular scene considerable time and thought. In writing, I weighed if the monster/ghosts fed on the human monster—in this case Bias—wouldn't they become the monster? In writing this scene, I decided it was not enough for Bias to be dragged to a bleak death. I wrote the character Bias as an immortal that was still vulnerable. I wrote in his vulnerability knowing that immortals have been killed by motifs such as apples, rings, bright sunlight, wooden stakes, and even silver bullets.

After locking that fifth script and numbering each scene, I measured the scenes in eighths of a page. This eighth measurement is related to the length of the film, as it assumes that one page of script equals one screen minute. For example, a scene with typed words that take up half a page, will take approximately 30 seconds of screen time. This measuring step is tedious, but critical in terms of forecasting how long it will take to shoot each scene. Consequently, it also helps uncover how long it will take to shoot the entire film. Being able to adhere to a shooting schedule, based on these measurements, would mean no overages to my budget. That said, the shooting schedule and the budget are kissing cousins.

After this measurement step, it was time for me to break down the script. This breaking down portion is typically a job for a first assistant, but without one of those

handy, this was another job for me to tackle. The script break down involves reviewing the script to ready certain elements for pre-production and production. It is a monotonous job with color coded standards established by the film industry. These standards involve creating a red underline for every speaking actor, a yellow underline for every extra with no lines, and a purple underline for every prop. Then, there are brown underlines for sound effects and music, not including those added in post-production. There is a circle added for every costume, and an asterisk for make-up or hair. After this process, it is easy to identify which scenes need which elements. For example, scene #16 might need prison costumes, hair and make up for one prisoner in particular, beds as backdrop props and special audio needs. With the color coding, all of these elements are easily seen in the script break down. This is important because every element costs. Breaking the elements apart in this way helped me to prepare an accurate budget. From there I can also quickly group scenes together for the most logical shooting schedule. For example, if there are two scenes with the exact same props and costumed characters, even though one may be scene #5 and the other may be scene #35, it is much more logical to shoot these two scenes back-to-back.

### **Visual Storytelling**

Instead of being set in a Gothic environment like some horror films, *The Colored Pill* is set in modern times. The majority of the film takes place in a country/rural environment. Like many horrors, the setting was specifically designed to take place at night so I could use the dark *mise-en-scène* (framing arrangement), tempered only by

shadows to enhance the overall creepiness. The dark night scenes were selected to parallel the darkest days of American history.

Location is a critical element of any narrative and holds a critical task, as the England-gray, isolated estate of gothic horror can easily attest. I used the setting of a barn to spotlight where horrible things might befall the protagonist, as opposed to a setting commonly used in horror films. The barn was decidedly a strange *unhouse* or *unhome*, in symbolism, of a dwelling place for the monster/ghosts themselves. I specifically chose the location of a countryside barn as an essential element in the majority of the scenes as a nod to the countryside farmhouse used in a classic horror film I drew from filmmaker George Romero's zombies in *Night of the Living Dead* (Streiner & Hardman, 1968), which grappled with issues of race, the dunghill of racist ideas, and the strain of racial tension in a horror genre.

A somewhat frightening thing happened during one of the night shoots. We were filming two actors standing inside the barn, just at the inside opening. Outside of the garage was a huge field, blackened by night. The location of our set was a barn separated from other properties by 30 acres. Once the sun has set, as far as the eye could see, there was nothing but blackness all around. This is why it was so creepy when during filming, a small pin light would sporadically blink on and off out in the field. Everything in the field was black except for this little light that would occasionally blink. This was so odd, but the fact that we were filming a horror film, when this strange occurrence took place, it somehow seemed fitting. Fitting, but admittedly, a little frightening.

During filming, there was a scene where former prisoners of Holmesburg Prison were freed, albeit, freed by their own deaths. One ghostly prisoner speaking about his former life shouts, “We wasn’t nothin’ [sic] but human guinea pigs! They call that medicine” (Lakota, 2017)? Cohen (1996) wrote that the monster “is a body across which difference has been repeatedly written” (p.12). In this example, my monster/ghosts offer a very different version of history and of medical experimentations than the more popular, lionized version, yet as the writer, I wondered if I was imposing a particular view and philosophy of America’s willfully blind history. I quibbled with my own bias in conveying this information. Knowing that films are extremely impactful, was I doing more than just conveying information? Though it was not my intention, was I using my monster/ghosts to shape history? Was I shifting from using the film to record life (film as a cultural artifact), to using the film to advance my own particular beliefs? To help me with this ideological concern, I stayed close to the research. I also constantly asked myself questions to re-investigate my intention for my plot, as well as every shot, every sentence of dialogue, and every camera angle.

I did use the monster/ghosts as a plot device to externalize unrecorded viewpoints. In so doing, I share critical information with the audience about the desire for vengeance for these individuals. The film’s monster/ghosts signal many things, including the social injustice of having this part of African American history erased. Parks (1995) offers, “so much of African-American history has been unrecorded, dismembered, washed out, one of my tasks as a playwright is to...locate the ancestral burial ground, dig for bones, find

bones, hear the bones sing” (p. 4). Like Parks, I too, heard the bones of my ancestors sing out for justice.

### **The Shooting Day**

The shoot worked like clockwork, mostly due to my well-orchestrated shot list. With that in hand, after shooting each scene, we would immediately set up for the next scene. A photograph of one of the scenes being shot is presented in Figure 5. The cast and crew knew in advance which scenes were going to be shot each day and in which order. I also placed this information on their call sheets.



*Figure 5. Shooting Interior Scene*

Production began with a call sheet that I custom created. The call sheet does just that, it calls every member of production to set. It is emailed to every actor, supporting actor, extra, director of photography, drone operators, and audio technicians.

I created my call sheet to include several elements:

- Call time
- Film title
- Date



- Producer/Director name and contact
- Weather forecast
- Nearest hospital to set
- Production office address and phone number
- Filming location including address and parking information
- Scene numbers to be shot for the day, page number in the script where the scene is located, and cast members performing in the scene

The call sheets helped me to stagger when varied people were to arrive on set. For example, the crew call and hair/make-up professionals' call were always earlier than the cast. I scheduled it this way to avoid bringing my actors in before I needed them. If I had not done this, it would have resulted in quite a bit of standing around for my actors as they waited for lights to be placed, or waited for the hair/make-up to set up their stations.

By the time I hit the slate (clapperboard) at the beginning of the take, and called out "Quiet on the Set" to designate the start of filming, the crew and I had actually been on set for several hours. With my shot list in hand, we began filming each scene. There were times, in my shoot, where we were filming an interior night-time scene during the day. In those cases, we first needed to darken the location—closing every door, stuffing towels under doors so light would not seep through, and even taping black-out fabric across some of the windows. This part of darkening the space got very creative, to say the least.

The filming day is like a dance. As it was my film, I always appeared on set first, well before call time. One of my self-appointed duties was to walk the location to make

sure that all was in order. Each day of shooting began with my policing the location—walking the set and picking up all trash, cigarette butts, craft service garbage etc. I made sure props had not been moved (for continuity in filming), food service for the day was confirmed, costumes were hung and ready, etc. Not far behind my arrival on set, appeared the camera operators, lighting and audio professionals, along with the hair/makeup and special effects team.

In terms of the chosen costumes, I allowed the circumstances of each character to dictate the costumes I rented or purchased. Obviously, to depict prison inmates of the past, I rented vintage-looking black and white striped uniforms. The same went for my physician and nurse medical outfits. For one character, Frank, with his harshness written into the script, I chose a dark, matching suit and tie and dressy overcoat. A photograph of the character, in costume, is presented in Figure 6. I chose well and the suit looked expensive, even though I picked it up at a second-hand shop.



*Figure 6. Immortals, Bias and Frank*

The dark suit and tie supported the character's business-side. For Bias, I chose a colorful T-shirt (custom made for this film), a leather jacket, and dark jeans. These costumes portrayed how much both characters were able to fit in with the humans by looking like them. For Fannie Lou Hamer and the accompanying women who walked along beside her on a country road, I chose costumes made up of dresses and purses that had a 50s-60s vibe, which in our current day, were not easy to find. Truth is, one of the dresses was not vintage at all, but when shot, even that dress fit seamlessly into the scene.

### **The Art of Cinematography, Sound and Music**

I love working with creative artists of all kinds. It cannot be overstated, how important it is to build a creative partnership during filming. In that, I was blessed with creative allies. As storytelling tools go, one of a filmmaker's more critical one is the camera. As the writer, I answer the *what* question regarding the film, but the cinematography—including color, lighting, and exposure—answers *how* the film will come together.

With the varied zooms, angles, depth of field, framing and lens choices, cinematography was a critical ingredient. Without it, I would not have been able to tell this particular story. Just as humans are more than just a fair-to-middling bag of flesh and bones, the cinematography part of the process involves more than just a grasp of film terminology or knowledge of how to use buttons on a camera. In order to nail each shot—whether they be establishing (shots at the start of the scene), long (filmed at a distance), bird's eye (looking down onto the scene), as the Director/Producer I needed to be aware of the varied ways to map out camera positions. A similar process was in effect

for decisions about framing (arranging actors, objects, etc. into the frame), cutaways (interrupting the shot by inserting something into view) as well as various panning and tilting, which are up-and-down camera movements. Of course, if I had it to do over again, I would shoot the entire film differently, but alas, hindsight is indeed 20/20.

In visualizing this film prior to production, there was one scene, in particular that I saw in my mind's eye, when I wrote the script. In that scene, I saw the camera roll across a field of tall grasses and lands, going toward Anarcha. Anarcha is screaming and bleeding, while atop a table in the middle of the grasses. I could not get that visualized image out of my mind prior to filming. The problem was, though I could clearly see the shot in my mind, on set my crew and I could not figure out how to best capture it. Blessedly, my drone operators also brought a steadicam camera stabilizer along. Using the steadicam did the trick, and allowed audience viewers to see the scene the way I envisioned it.

### **Sound Design**

Great sound design is truly an art. Whittington (2007) states, "The strength of an image and sound construction ... is not simply a matter of synchronization. Rather, it is one of stylistic sensibilities within the genre framework as well" (p. 99). In the making of *The Colored Pill*, the artistry and complexity of image-sound design was considerable.

As an example, there is one very short scene in the film where a character walks through a dark room and moves to a light switch, and flips on the light. Sounds as simple as a blues diddley bow, but from a sound design perspective, it was anything but simple. Similar to the taut string of that diddley bow nailed to a wooden board, in consideration

of the tenseness of the scene, I tightly fastened no less than five different sounds plus a high-frequency hum—all to help turn on a simple overhead light. Why? This was done to underscore a sense of creepy apprehension into the scene. To accomplish this, I layered sound designs of an electric buzz, clicking, fluorescent filaments, while I amped up the sound of an electric hum and the ambient room buzz. All these sound design layers were added to the sound track for the three seconds it took for the on screen light switch to be flicked on. Some may wonder if adding so many layers was excessive. In my view, it was critical to create edginess to the mood of the scene.

In this same scene, I added quite a bit of asynchronous sounds because I know that dislocated sounds—sounds where the audience cannot track their exact location—cause anxiety and activate a feeling of suspense. For a horror, anxiety is an effective element to induce onto the audience. The specific asynchronous sounds I added were squalls of wind, ominous thunder rumbles, water dripping, boards creaking, people groaning, raspy growling, and heavy breathing. From a sound design perspective, I also added a number whooshes, metallics, and scary sound transitions.

In the opening film sequence, I honed in on numerous non-diegetic sounds—sounds that appear to take place off screen. Non-diegetic sounds are invisible to the audience, and include music, voice-overs, cars honking outside of a residence, etc. In the case of specific crowd footage used, I added the non-diegetic sounds of a crowd chanting, cheering, marching, and also applause. Throughout the film, I also added a few low frequency sounds to enhance the overall feeling of tension. Sonically, I manipulated the

actual volume (don't films seem to be getting louder?) during certain scenes, to better set up the overall atmosphere.

In an early scene, where my main character walks through a series of crumbling environments, a number of sound design elements were added. For example, I bristled the scene with unsettling music, namely metallic chords. Kassabian (2001) articulates that “music draws filmgoers into a film’s world” (p. 1). The focus on the low, ambling and unhappy music not only produced an eerie feeling, it also endowed this sequence of scenes with the feeling that *something* is getting ready to happen. The unsettling of the audience was a very effective tool for me to utilize, in order to support the genre of horror.

It is in this early scene that the audience is introduced to Bias. In this scene, I show Bias’ point-of-view, as he visits old haunts, which are places he has ravaged. It was important to introduce Bias over scary footage and sounds so the audience would know, early on, who he is and the horrible things he has done. This scene also established what Bias thinks of himself. The mindset of this character is critical for the rest of the film in order to fully understand the ramifications of the things he has done.

At this early scene, the audience’s only connection with Bias is through his voice. In these early scenes, the audience hears his voice, but does not see his face. I did not want to spoil the suspense of the audience seeing Bias for the first time for as long as I could to engage their imaginations, but also because I wanted viewers to focus their attention on seeing the world as he does. This meant the audience could just hear his point of view, how he views his story, and how he justifies himself.

One of the storytelling tools I used, again in an early scene, to accomplish the engagement of the audience's imagination was to allow them to *hear* children talking and laughing, but not to see the actual children. This technique allowed the children to come across as disembodied spirits, which they were. This was reinforced for the audience because as they heard the children's voices, they were seeing a decayed place where children clearly once played.

Since *The Colored Pill* is a thriller/horror, the music and sound effects needed to fuse together to sustain tension and create an anxious anticipation of doom. As a filmmaker, I know the anticipation of the threat is often greater than the actual threat. This meant that I needed to constantly layer thunder rumbles, eerie whispers and mournful wind to foreshadow the scary terrain. I also needed to keep a keen eye on music selections, particularly those heavily steeped in low tones, in order to allow the sonic construction of a lurking presence to supersede the actual footage.

Bias Voice-Over: Where do I begin? My story is so much larger than anything I could tell you right now. I don't have a ghost of a chance of being believed anyway. I supposed I could show you the things I've done, but then you would think of me as a monster (Lakota, 2017).

To the above words of dialogue, I added music beneath Bias' voice over, but I also added a stinging metallic sound design. Hutchings (2009) shares that sonic "stingers serve as an assault on the audience to unnerve and offer entry into a state of psychological disorientation" (p. 223). After that early line of dialogue, the camera ambles from outside to the inside of the crumbling Fernald School for Children, with its dark shadows, caved in ceilings, and flashes of spooky faces.

Referencing Bias' thoughts about how he may appear monstrous to others was important as it oriented the audience to the possibility that Bias just may be a monster. As he says his lines, the audience is looking at a location that only a monster would want to visit. Since Bias actually is a monster, albeit a monster that looks human, it was important for me to place the question of whether or not he is a monster in the audiences' mind early on.

The inclusion of sound design in this scene, and almost every other scene, was critical in order to pull off a suspenseful effect. While I had decent visuals to work with, I believe these early scene worked, in invoking terror, because of the added sound design of creaks, groans, thunder, whispers, and whooshes—all of which forewarn the audience that something scary is approaching.

In another example, toward the end of the film, the character, Frank, drives alone on a dark road. Isolated, the audience hears the steady crunch of gravel under his tires, due solely to the magic of sound design. The actual sound of his driving, quite frankly, was not scary. The hooting of an unseen owl—another sound design addition—added to the eeriness. When Frank rolls down his car window, when the nighttime sounds of insects seep into the vehicle, the crackle of thunder—none of these things were actually there, but instead, they were added sound design elements.

From focus groups, I learned that one of the scenes that audiences found hair-raising was the scene when Frank broke another character's finger. This particular piece of footage was unfortunately shot from only one direction, so my visual storytelling was limited. Going back to re-shoot that scene was cost prohibitive. To compensate, I added



sonic information to the scene with the finger breaking. Specifically, I added a slowed-down sound of a piece of celery being broken, and placed it into the scene at the exact moment when Frank breaks the finger. It worked! Audience members' perception of terror in that scene did the remaining work, which I believe is why the focus group later commented on the creepiness of that scene.

In keeping with the before mentioned *The New York Times'* *Anatomy of a Scene*, for the final section of this chapter, I deconstruct scenes from *The Colored Pill*, using this structure. For this final section I have chosen six scenes from the film, to explain my behind-the-scenes thoughts and actions in more detail.

### **Anatomy of a Scene #1, Opening Sequence**

In the film, I use immortality as a curse reserved for those who must be taught a lesson. I wrote this into the script. I also show the loneliness and emotional pain of being born with immortality. In so doing, I mimic the expression of illness. I counter this discussion about beings that cannot die, with undead monster/ghosts. The first visual, after my production company animation (but before the opening titles), is a quote. The quote, written by Sophocles reads, "Nothing vast enters the life of mortals without a curse."

Enhancing the quote is a smoke effect added by creating a layer in Photoshop. I punctuate the quote with sonic enhancements, in this case, two hits—one regular and one bassy. Using this quote at the film opener sets up a warning of the scariness to come. It also helps to unfold the topic of bias that is pervasive throughout the film. As the music blasts to an end, I used a cool special effect so the words of the quote would seemingly be

erased away. Juxtaposing my Sophocles quote with footage of racial protests was designed for the audience to take seriously the notion of a curse on mortals.

Going past the protest footage, the audience sees a black screen, over which they hear former President Barack Obama saying, “America, we know that bias remains.” I chose this audio because it uses a very recognizable voice of Barack Obama. In using his voice, I am borrowing from the credibility of the former President. Pragmatically, it also worked because it gets the word *bias* into the audience’s ears early on. To enhance the sound, I added a reverb onto the word *remains*. Following that word, I added a sonic hit, for emphasis.

Bias Voice-Over: What would you do if you discovered that bias in the world were a real, living, breathing spirit? What if I told you that every injustice that has plagued the world was because of an immortal presence that you cannot see, smell or touch, unless, of course, I want you to (Lakota, 2017)?

The concept of bias, and the things that bias has done in the world, was instrumental to the film, so I knew I needed to repeat the word often and quickly. From there, I take the audience into an old dilapidated building which once was the Fernald School for Children. Throughout this particular scene, the viewers are privy to Bias being haunted by, and haunting the places where he holds memories. Presumably he has *returned to the scene of the crime*, so to speak. There is no celebration in his tone, and no closure for the things he has done. Instead, as he walks through the contaminated and decimated places of his past, he reminds the audience that it is he that has brought about trauma to the places they are witnessing. During this scene, the audience cannot see Bias, so at this point; he is a spectral presence bearing witness to the things that have taken place within the crumbling walls of the buildings. In designing the scene in this way, I established a

seamless integration between the physical geography of the space, and the testifying voice of Bias.

### **Anatomy of a Scene #2, The Human Monster**

Bias cannot classify himself by a single descriptor. He is a monster. He is also ideologically, and philosophically, human. The representation of the human monster in this scene was constructed by getting inside the head of Bias. This portion of the film is told from Bias' own perspective. It is his chilling, first-person account. The character describes himself this way: *I am the tools on the masters' belt ... the eraser of history. I am the master of disguise. I created the tests that normalize inequalities.*

Here, the monstrosity of this character was made visible to the audience, as he documented his fatal accomplishments compelled by inserting himself into the world. Depersonalizing the character in this way, and showing how he was conscious of his monstrosity, made him easy for the audience to revile him. His words show the viewers exactly what is at stake—what will be lost if this human monster is not stopped. Because Bias' appearance mimics other humans, he goes undetected in the midst of humanity. This means that in a social context, Bias is able to weave in and out of monstrosity. Further challenging monstrosity, the film shows there is little in our culture that physically distinguishes the monsters from the non-monsters. The double entendre, visible to the discerning viewer, is the fact that the monster-ghosts depicted in the film, cannot perform this little trick as the main character can, as the distinguishing characteristic of their dark skin perpetually anchors their identity of being monstrous.

From time to time throughout this film, the figure of the monster needed to be more pronounced. To represent the main character as more domineering, and in keeping with an intention to present him as a human protagonist/monster, I enhanced the actors' voice. Giving his voice a sinister connotation, in post-production I adjusted his tonal quality, and lowered his pitch. This resulted in giving his voice a much more menacing quality, indicative of traditional monstrosity.

The trick of the film, however, was in troubling the audience's desire to *pull for* the monster/ghosts—who hate Bias—as they are both victims and monsters, in their own right. This was an important piece because, later in the film, Bias appears frightened by the monster-ghosts. The expressions of fear from Bias, at seeing the monster-ghosts might make it easy for the audience to forget that he, Bias, committed monstrous acts against those very monster-ghosts. I wanted the audience to be forced to decide, which one of them is the monster.

I had this scene shot in the gorgeous Riverfront community in downtown Denver. Katz (1991) reasons that, “from the moment a script exists and work commences, the director should strive to make every shot and every sequence count” (p. 6). With this in mind, I filmed in this wonderful location to superimpose the point that this beautiful, yet broken world, is inhabited by things unseen, in this case, a bias that moves around freely. I specifically positioned this particular shot—with Bias in the center of the frame —so the viewers' gaze take in the gorgeous surroundings in the background, but stay predominantly fixed on Bias, in the foreground. Pinedo (1997) notes that, “Horror films avoid locating monstrosity in the city where violence is, as a matter of public record, a

routine element of everyday life” (p. 112). I specifically chose a city location for some scenes, to violate the typical horror genre aesthetic that locates terror in the suburbs.

*Bias Voice-Over: I am the phantom in the fog. The manifestation of scientific knowledge (Lakota, 2017).*

The dialogue in this scene is meant to function in such a way as to show Bias’ pride for himself, and also to engender some nervous shivers within the audience. There is a strong camera pull-back here as the audience gets a look at Bias’ face for the first time. As Bias’ voice rises and we see his face, the audience gets a first glimpse into the incongruity between how he looks (human) and who/what he really is (a monster).

For the scene where Bias introduces himself, I chose an *arc shot*, which is a visually engaging technique whereby the character stands stationary, while the camera tracks around him in a circle. I chose this shot for this scene because I knew Bias was going to reveal several components of his identity, and I knew an arc shot would visually complicate the character, as he describes himself.

The *arc shot* is sometimes known as a *dolly shot*, and within that term, lays a challenge I faced. On the day of shooting this scene, I did not bring a dolly. My camera person also did not bring his dolly. It was completely my mistake and I take full responsibility for not having the dolly. That piece of equipment was something I should have ensured would be there, particularly since the shot list for the day, which I created, called for the arc shot and the need for a dolly.

Needless to say, getting the shot without a dolly was challenging. In the end, we persevered. The shot was not as smooth as I would have liked, but without the dolly, we

had to improvise. In the end, the cinematographer held his tripod (with camera attached) and walked around the actor. Without the dolly we had to make do, and the cinematographer's idea for getting the shot, did work.

Adding to the challenge of not bringing the dolly was the fact that the actor was just recovering from surgery. He was a real trooper in even agreeing to shoot the scene so soon after surgery, but I was quite concerned about his health all throughout the shoot. As if that weren't enough, the shoot was scheduled for a night that ended up being frigid, Colorado temperatures. Truth is, we had actually scheduled to shoot the scene the week prior. That evening was bitter cold as well, and I could see the actor was in physical distress. This was a very important scene to show the haughtiness of the character, Bias, and I did not think that would come through on film if the actor was in pain both from his surgery, and from the biting cold of the night. Though the actor was very brave and said he could continue, I ended the shoot, and rescheduled. My actor was immensely grateful to get out of the cold, and I knew I had made the right decision to consider his health over filming. On the day of the rescheduled shoot, it was again a cold evening, just not as cold as the prior shoot. The actor, still recovering from surgery, assured me he was okay to finish, so we pushed on and got the scene. Not wanting to stress my actor further, or put his health in jeopardy, I did not want to reshoot the arc scene over and over again until it was perfect. We shot what we could, finished, and quickly got out of the cold.

*Bias Voice-Over: I am the eraser of history! [Pause] But now, I am the one being tormented? I am the Other? And for what? For unleashing myself—my exquisite bias into this wretched world (Lakota, 2017)?*

The words of Bias' self-identification were carefully crafted. I made sure I included a line of dialogue about his being considered *the Other*, in a nod to victims of race based medicines and experimentations who actually were Othered. Additionally, in this scene, I had a real opportunity to juxtapose who Bias is, as a human monster, living among people who have no idea who he really is.

Bias Voice-Over: You always defer to my judgement. Most of you won't even go out into the world without me. I am that little voice inside your head that tell you who is right, who is attractive. Without me, most of you don't know if someone who sits beside you on the train is good or bad, smart or stupid (Lakota, 2017).

The connection Bias has to people all around him, who he disdains, was important to show, so I picked a beautiful location to juxtapose Bias' black-hearted nature.

### **Anatomy of a Scene #3, The Confrontation of Two Immortals**

The scene of the confrontation between two human-looking immortals, Bias, and Randy Diamon who brilliantly played the character, Frank, is a big moment in the film. Bias' intention in going to meet with the Boss, is to plead for a stay on his life. Instead, Frank awaits him. Frank has plans to kill Bias. For Frank, the meeting is actually a ruse to get Bias away from everyone, hence, meeting at a remote barn, so he can have him murdered.

By placing the immortals within the open isolation of a barn, I jab a finger at the social disconnectedness of humans. After all, the fact that Bias is a non-human who walks undetected in a tangle of humans, paints a bit of a fractured portrait of humanity. If nothing else, it speaks to social power in terms of who is seen, and who is not seen. Also, in selecting a barn, I also situate the monster within a familiar/unfamiliar space. Because

most of the film takes place in this unidentified rural setting, with very few stylized visuals and minimal set decorations, the specific timeframe could be the past, present, or future.

The selection of the barn location was quite a story, in and of itself. My production assistant and I had decided to use two separate cars to drive to the barn. We both had another engagement after meeting with the barn owner, so we thought using two cars would be prudent.

I used a navigational system to direct me to the barn, but I found out after the fact that my GPS took me the long way. I remember driving for what felt like hours to get to the barn, as it was significantly west of my home. Halfway there, I decided this would not be a good location. It was just too far. I could not imagine that my actors would want to drive to such a remote location either. I convinced myself, mid route, that the location was just, all around, not a good idea. I told myself that I was going to show up, meet the barn owner, but decline the opportunity to use the location for the film.

The barn was set back off of a rural road, so when I got close to the address, I really could not see it as I pulled onto the dirt road which led to it. The location photograph is presented in Figure 7. Finally, the barn came into view.





*Figure 7. Film Location, Boulder, CO*

Wow! That was my first reaction to seeing the barn! It was huge; and it was constructed to look more like a large home, than a barn. The acreage around it was fantastic—amazingly scenic, very open, with the foothills of Colorado close by. I knew instantly that despite my self-talk on the drive there that I was going to grab this location. In the end, I am glad I did, though it did make for some very late nights traveling back to my home at the end of a long day of shooting.

The scene where Frank and Bias meet, begins after the audience sees a gorgeous aerial of pine trees sandwiched by a winding road. It is a beautiful aerial shot, which I purchased to show the ambition of this film. I knew a large aerial would make my film seem bigger than it actually was. The meeting between Frank and Bias was actually my first day of shooting, so we were all just beginning to get to know each other on set. It ended up being a good, easy start to filming.

Earlier in the scene, as the audience is viewing another gorgeous piece of aerial footage of downtown Denver, we hear two radio announcers talking about

pharmaceutical companies and racialized targeted drugs in a talk-radio type program. I had originally selected a television broadcast of news anchor, Peter Jennings, in a segment where he actually discussed racialized medicine. Unfortunately, the purchase of that particular television broadcast was outside my budget. The radio announcers I used were actually *broadcaster-sounding* talent, whose voices I paid to read my script dialogue. These voices were recorded in advance of filming, so it was easy to insert them over the aerial footage during editing.

From the aerials, we get into the part of the scene where Frank drives alone to the barn, to meet Bias. This driving up to the barn portion, actually had to be practiced a couple of times. For such a simple scene, for some reason we either did not have the camera positioned in the best location to get his car moving in, or the position of Frank's feet once he got out of the car, was off. By the time we actually got the shot, the sun had set, and we had lost our light. With that having taken place there were some concerns about continuity, but luckily we managed to work out most of our lighting issues in post-production. In post-production, we added a nice visual effect—a glow of lights—to represent a cars' headlights shining against the graveled road and the dark, menacing barn. The effect worked wonderfully and looked completely believable.

During the filming, I actually used two different barn locations. For most of the indoor shots, I used the beautiful barn located in Boulder, but that structure was very contemporary looking from the outside. For that reason, I used a real, historical barn I discovered in Aurora, Colorado, for the outside shots. The two barns worked very well together, and I am sure my audience never noticed that there were actually two barns.

The first real scare in the film takes place when Bias arrives at the barn, just moments after Frank has arrived. I wanted the introduction of Frank to be a bit intimidating, so I needed to set an ominous atmosphere for the scene. From a sound perspective, viewers hear a spooky sounding owl which plays right into some of the conventions of horror films. The only other sound, other than the outside ambience added in post-production, is Bias' unsteady footsteps on the gravel outside. Again, in post-production, I added some scary ambient sounds, just to get the audience ready for the upcoming scare inside the barn.

From a visual perspective, I directed Bias to walk slowly into the extremely dark barn, knowing I would add post-production phantom voices whispering all around him outside. All total, I have a dark night, a sinister barn, and voices all around that suggest things unseen. All of these things were deliberately designed to suggest a sinister presence. I was inspired by a formula for fear quote attributed to filmmaker Alfred Hitchcock in *Halliwel's Filmgoer's Companion* (1984), "There is no terror in the bang, only in the anticipation of it". All of the things that go bump in the night—the creaking of the barn door, the crunch of footsteps on gravel, and more, were necessary ingredients needed to increase the anticipation in the audience that *something* was about to happen. So, again, I heightened the sense of anticipation. Planting these kinds of seeds of fear and anticipation went a long way toward the worry-filled buildup of the scare, as opposed to the actual scare.

As this scene unfolded, the audience hears a background of wind. The element of wind throughout the scene was introduced in post-production and sliced in to contribute

to an overall petrifying effect. The subtext of the scary music added, coupled with the isolation of the barn, indicates to the viewers that Bias' fate is uncertain. To reinforce this point, I included a close up cut of Frank, with an underhanded smirk. Initially, the audience may not understand the meaning of Frank's smirk, but it was cut this way to artistically show the truth of who Frank is. As the camera zoomed in closer on Frank's face, it is clear from his expression, that his motives are treacherous. Because the audience has seen Frank's devious facial expression, they are *ahead of* Bias, so to speak, as they know what Bias does not—that Frank came to the barn with deceitful intent. This is all a part of the fright complex I thought through to add to the audience's suspense.

Later, in this same scene, I had Frank stand back, out of the view of Bias. The script called for Frank to not answer Bias' call. This combination of not seeing Frank while hearing Bias call to him, set up a perfect place to use a typical horror technique called a *jump scare* which is a hushed or quiet cinematic moment interrupted by an unexpected and external image or noise. Allowing Frank to emerge from the darkness may have been somewhat expected, but worked very nicely for the first real scare of the film.

#### **Anatomy of a Scene #4, Anarcha Westcott, 1849**

This scene is a re-enactment, which focuses the audience's attention on 17-year-old slave girl, Anarcha, played by the actor Desiree Geraldine. This scene shows a horrible, bright red bloody sheet, and Anarcha twisting and writhing in pain atop the sheet. The scene represents one of the flash backs from Bias, as he reflects on the things he has caused.

To set up the scene, Bias has just had a conversation with Frank about his (Bias') work. Up until now, the audience knows very little about Bias other than his emotional landscape depicted in a strange sense of dread about even showing up for the barn meeting, and his disbelief that a plan he and Trey (played by actor, Adam Phillips) have created. I wrote this outdoor scene so the audience could visually experience some of the depraved things Bias has done in the past.

The backdrop for this scene was outside of the barn location. The day of shooting could not have been more gorgeous—with bright blue skies, white, puffy clouds. It was the perfect, natural lighting to shoot a gory bloody scene.

From her frenzied screams (enhanced, of course by sound effects), I knew viewers could see Anarcha needs help. The leap is for viewers to know that she still needs our help, by accepting the truth of her story and making sure that kind of thing never takes place again. I did not want the audience to only see her “Otherness” as a site of powerlessness, but to exercise their own power and shift their thinking about history.

As the audience moves into this particular scene, I had a great piece of music that eased them into the scene. I knew the visuals—the dehumanization of Anarcha—was quite graphic. In fact, the scene was so graphic that I needed to lull the audience into the scene. For that reason, I chose a smooth, jazzy sound with a great vocal, and a great message to support the scene.

The lyrics and pace of the song I chose for this scene—“A Dark Cloud Is Coming”—together with a high angled camera, was the perfect way to depict the real-life racialized tragedy. The following is a snippet of the lyrics from the Moby (2018) song:

I went down to the river  
I went down to the river  
I went down to the river  
To see if I could be saved  
'Cause a dark cloud is coming  
A dark cloud is coming  
Said a dark cloud is coming  
Come for me now  
(Moby, 2018)

The repeated lyrics of “A Dark Cloud is Coming” (Moby, 2018), countered the blue-sky-visuals of the scene. This music, chosen because it would not take too much of an imagination to see monster/ghosts who will soon be coming, worked perfectly here.

This visceral scene showing Anarcha’s mutilated body, moored to a bloody table by several doctors, is powerful. The scene is an effective introduction of Dr. J. Marion Sims, who later became known as the *Father of Gynecology*.

*Bias Voice-Over: That’s Dr. J. Marion Sims. He performed over 30 surgeries on little Anarcha. That was my doing. I convinced Dr. Sims that African girls had a higher pain tolerance than White girls (Lakota, 2017).*

The scope of the historical telling for this scene required that I remind the audience that the story of Anarcha Westcott is a true story. To do that, in post-production we added a text card over part of the scene so I could explain who Anarcha was, the year in history, and a bit about what was being done to her in the scene at the hands of Dr. J. Marion Sims.

Like many Southerners of the time, Dr. Sims ascribed to slave-ownership, and had the distinction of being viewed as a preeminent gynecological surgeon and thus, thought of as a “pioneering hero” for medicine and experiments on African females. If

Dr. Sims was the *Father of Gynecology*, then surely Anarcha Westcott was the *Mother of Gynecology*, as Dr. Sims operated on her 30 times, without anesthesia, until he perfected his surgical technique of repairing the vesico-vaginal fistula. In this scene, I chose not to shift the dehumanizing male gaze—clinical or otherwise—of Dr. Sims and his physician associates, on the pained body of Anarcha.

*Dr. Sims: She can take the pain! These girls can take the pain!*

I also chose to include his callous remarks in the film, a documented quote, about her ability to take the pain. Foucault (1994), speaking on the dilemma of medical obligations, asked, “Can pain be a spectacle?” (p. 84). In the audience’s witness of the exploitation and racial domination of Anarcha’s black body, they experience the medical fictions Dr. J. Marion Sims ascribed to regarding the pain tolerance of Black women. I hoped that audiences would see how the physicians exoticized her body. I also hoped audiences would ask, if women like Anarcha could “take the pain,” why would physicians need to hold them down to a table?

The immense emotional depth performed by the actor for Anarcha, was astounding! Performance scholar Dwight Conquergood (1991) wrote about “the body as a site of knowing” (p. 180). In what Conquergood would describe as participation/observation, I stood close by as the scene was filmed. I watched, listened, and witnessed as the actor absorbed the historical knowledge of Anarcha, and allowed the fullness of the character to come forward.

African American historian Ula Taylor (2008) educates that when writing about black women from the past, we should speak to the silences of their lives. This notion of

speaking to the silences is implied in the hush of the sick child's words, "*Tell someone I'm here*" (Galeano, 1992, p. 72). They are also implied in the words from Madison (1998), whispered throughout this study, "*I am here in the world among you*" (p. 173). As mentioned in chapter one, the body speaks in two voices. One voice is biological. The other voice is biographical. I got the concept of speaking to the silences, across to my viewers, specifically by sharing the lives of those who could not speak for themselves.

At this point in the shoot, I listened. I recognized there was very little I could offer, as the baton had been turned over to the actor. This scene was a profound point of the film performance alchemy where the actor turned the research into meaning. It teetered on the edge of being therapeutic. In so doing, the actor skillfully allowed her body to become the site of knowledge that Conquergood (1991) spoke about, as she transformed her performance into "an embodied practice" (p. 180).

I was in awe at the actors' ability to dig up the ancestors, and unearth both the fear and vulnerability of a young girl whose body had been violated. I was also in awe when, much later in the film, this same actor transformed into a human ghost. There, she adopted the predatory gaze of a ghost, ready to take revenge. I was standing just out of range from the camera during the shooting of the surgical scene, and even though I had written the scene myself, it literally brought me to tears. It was so very powerful and emotional, and a scene I will not soon forget.

*Bias Voice-Over: Anarcha wasn't the only one. Dr. Sims operated on others. Every one of them badly hurt. All under the guise of science (Lakota, 2017).*



This scene was a part of ratcheting up of audience tension about scientific experiments. I used it as a prelude to introduce the most current experimental product, BiDil®. This scene was a critical moment because I knew that any audience member with a heart would be spellbound by watching a young girl, regardless of color, screaming and bleeding. The temperature of the scene spoke to pain, cruelty, inhumanity, and suffering. These things made up the tone that I established with the audience, to get them on edge for the larger film take away.

In a later scene, I show Anarcha transformed as a monster/ghost. That scene, where a previously repressed Anarcha has transformed, sets the audience up for Bias having to face the monstrosity of his actions. Film scholar Robin Wood (2003) provides the term “return of the repressed” to contextualize the monstrous conflict between humanity and its monsters (p.69). One of the things that is different about *The Colored Pill* than other horror films is the fact that Anarcha’s actions do not depict some sort of slave rebellion. For me, if Anarcha is the monster, as in Frankenstein’s monster, then bias is the creator of that monster.

### **Anatomy of a Scene #5, Holmesburg Prison Sequence**

Even though there was rightful worldwide outrage over Nazi medical experimentations that took place in death camps, my research uncovered the fact that in America, between 1950 and 1960, thousands of monstrous instances of racialized medicine and experimentations took place, with no tribunals. Obviously, I could not reenact all of those ugly occurrences. The filming of instances that took place at Holmesburg Prison would have to suffice as a symbol of many other atrocities in health.

In Holmesburg Prison, aka The Berg, Black bodies were once again used to *contribute* to medical advancements. This is an ugly reality about our collective history. Recognizing how disturbing it is for my audience to take a long, troubling look back into that history, I tried not to belabor the point. I let sound do quite a bit of the heavy lifting in this area. Besides, I did not have the resources to showcase all of the perversions that had actually taken place. Instead, I chose to stay soberly focused and just tell the truth. "And you shall know the truth, and the truth shall set you free" (Book of John 8:32, The New King James Version). I aimed at presenting the historical information in a somewhat straightforward manner, so I could engage my audience, not turn them off. I certainly did not want them to turn away, or that would have defeated my purpose in using the film as a tool for knowledge enhancement.

While dermatologist Dr. Albert Kligman, in charge of Philadelphia's Holmesburg Prison, made millions of dollars, Black inmates were reduced to nothing more than research subjects. They underwent some of the most gruesome experiments, often leading to their own demise. I learned from my research that closed off from the watchful eyes of society and inside the cell-slamming penal environment, the University of Pennsylvania and others found a way to test and tweak pharmaceuticals and personal hygiene products on inmates. Cobbled together with what can only be described as quack medicine, many inmates were administered test cosmetics, powders and shampoos that caused baldness, extensive scarring, and permanent skin and nail injuries. Describing the backs of inmates, Author Harriet Washington (2006) said they were, "so covered by flayed, discolored and scarred skin from various patch tests of chemicals, that the distinctive checkerboard or

striped skin was a sure tip-off that the man was an ex-con” (p.249). I gave the writings of Washington to my special effects professional, to assist her in the design of prosthetics to indicate severely scarred skin.

The depictions of these scenes in *The Colored Pill* showed inmates who had experienced human experimentations and medical tortures. These incidents are the dark, forgotten memories of racialized medicine that I shed light on. As a society, we have ontologized Blackness just as we problematize the desire, in the medical community, to keep these truths hidden. These scenes formed a narrative arc for the film. Significant to this particular sequence is the fact that the inmate characters are shown as monster/ghosts because of the human experiments. In showing these former inmates as monster/ghosts, I force the audience to confront monstrosity via the connection between a mythologized history and the personal narrative of these individuals. Here, the audience is forced to confront the actions of the past, while facing their own negative reactions to monster/ghosts that now thirst for revenge.

In order to make the prison scene work, in a much more palpable way, I added music. I also ensured that I had precise image-to-music synchronization at every cut away image. In so doing, I was able to introduce a sense of hard times, dread, and loss through the words of the actual musical score. Originally slotted from the Holmesburg prison scene, in editing I changed the Skip James (1931) fingerpicking song, “Hard Time Killing Floor Blues” to another scene. Here is a bit of the lyrics from that song:

Hard times is here and everywhere you go  
Times are harder than ever been before  
You know that people, they are driftin' from door to door  
But you can't find no heaven, I don't care where they go

People, if I ever can get up off of this old hard killin' floor  
Lord, I'll never get down this low no more  
(Skip James, 1931, On James Paramount Record Label)

The emotive impact of the Skip James song I chose for this scene evoked a sense of hopelessness. Concerned, as I was, in using music that would be viewed as stereotypical, I actually had qualms about using this piece. It did not keep me up at night, but I was sensitive to the fact that past musical accompaniments in film have used the kind of practice that historically suggests foreignness. The practice I am speaking of is that which pairs Asian music only with films with Asian topics, or Eastern Indian music with films with Eastern Indian topics. I double and triple checked myself, to be sure that I had not slipped into that kind of exoticized behavior while using the Skip James song.

Scholar Dwight Conquergood (2002) pointed to songs as an intervening strategy for knowledge. In many cultures, music and songs are not just critical to the telling of history, they *became* history. In Conquergood's (1986) essay, he proclaims that music was not just a "cultural performance" (p. 149). It was also functional. In the end, I judged the arresting "Hard Time Killing Floor Blues" music on the strength of the tone it conveyed, and selected it as an appropriate method for the telling of history.

*Bias Voice-Over: Under my leadership, Holmesburg Prison performed experiments on men of color. Perfume. Hair dyes. DMSO drug studies (Lakota, 2017).*

With the dismalness of the Holmesburg prison scene, I needed to make some specific decisions about the films' color palette. For the scene, I felt we needed a drab, forlorn tone. The cinematographer did a beautiful job shooting the scene, but to create a much bleaker look, I tinkered quite a bit, with the color palette during the post-production

color grading process. At first I darkened the scene, and then applied several different Look Up Tables (LUTs). While those techniques helped, I eventually settled on a subtle grainy and desaturated tone so the film would exemplify one that has been dipped in a flat, colorless environment. Symbolically giving the impression that because of the experimentations, the inmates lives had been somewhat wiped of a full spectrum of color. I was able to accomplish this level of desaturation without totally degrading the footage the cinematographer had worked so hard to provide.

The placement of sound effects in the prison scene was a fun and necessary element to add in order to build tension. From the opening sequence of cell doors slamming, chains rattling, and the eerie walla (individuals in the background screaming), it was clear that the sound effects were going to greatly enhance these scenes.

*Inmate T-Bone: They gave me something new—about a month ago. They said—b-b-behind Cell Block H. They said—they said—I should drink it. My-my-my mind h-h-hasn't been the same—since, but I ain't all the way crazy yet (Lakota, 2017)!*

What helped the audience connect to the prison scene was the outstanding performance of the actors—David Rose and Jamil Kwama—who played Holmesburg prison inmates. Their characters had been mentally and physically damaged by racialized medicines and experiments, and the actors connected beautifully to those facts. Even before editing, I was quite impressed by how effortless the actors made the prison scene come to life.

There were a couple of visual elements also worth mentioning about the Holmesburg prison scene. First, I used a horse stable location to symbolize a prison

setting mostly because, in full transparency, I did not have access to a prison. However, one of the things I accomplished with this locale was the inhumane treatment inmates endured. In the end, using the horse stable location as a prison worked perfectly with the dialogue which shed light on how these prisoners were treated like animals, shown in the way they were standing in what was clearly a confinement for animals.

Inmate Big Nate: The Berg, got my body all marked up. Put me in the Klondike in August. With the windows shut. The big oven, they called it. Tried to cook me to death. They give me these pills. They say it's for the pain, but they make me hurt worse (Lakota, 2017).

The Klondike, at Holmesburg prison, was nothing less than a torture chamber. There, inmates endured the worst kinds of experimentations, which included exposure to extreme heat, described by Inmate Big Nate above. The close space I used in this scene was intentional, not just to indicate inmates being caged, but to show how the men were entrapped closely together, almost as one body.

*Inmate Big Nate: YOU DON'T KNOW WHAT IT'S LIKE TO BE MARKED. WE WAS NOTHIN' [SIC] BUT HUMAN GUINEA PIGS! THEY CALL THAT MEDICINE (Lakota, 2017)?!*

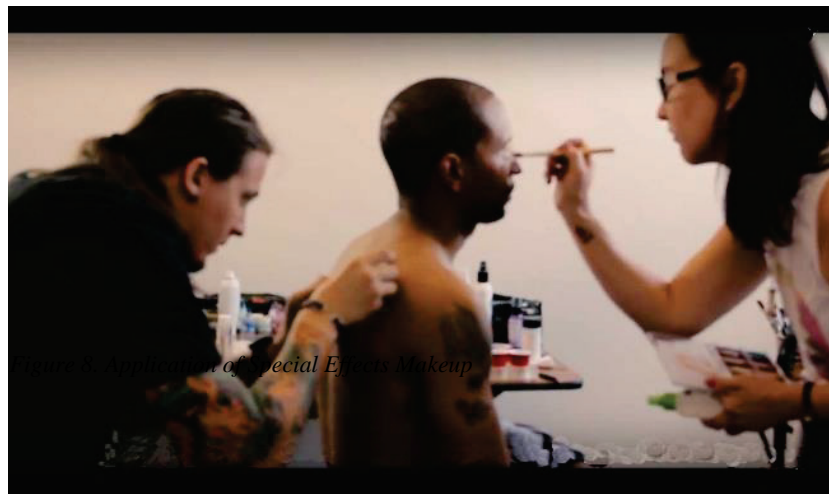
In this scene, Big Nate—a monster/ghost breaks the fourth wall performance convention, and speaks directly to the audience. This series of scenes were particularly important to the film because these are the moments when the inmates come back to life as ghosts. The social context of this scene presents the monster/ghosts as angry about their discarded status, as well as about the racialized experiments they endured. The expression of this anger is important and will be instrumental later in the film when I

decenter the privileged status of immortal bodies (stand-ins for humans) placing emphasis on nonhuman bodies in the form of monster/ghosts.

I could not illustrate all of the horrific things I found in my research, which included Black bodies that found their way to dissecting tables, operating amphitheaters, classrooms and experimental facilities (Blake, 1980; Humphrey, 1973). Instead, I hoped to get across the premise of the multitude of *for-Blacks-only* experiments, and the way those experiments rested on very faulty biological conceptions of race.

*Bias: It wasn't the first time I marked people. I used the threat of foreign disease to mark Mexicans. All to advance bias in health (Lakota, 2017).*

An interesting visual element for the prison scene was the special effects of making scars on the actors' skin to show the results of medical testing. A photograph of special effects makeup being applied is presented in Figure 8. A huge scar across the eye



*Figure 8. Application of Special Effects Makeup*

and several scars snaked across the back of one of the inmate actors. Creating these scars called for working with a special effects specialist. This was a new experience for me in

filmmaking. I met this particular artist through a friend of a friend, and had only seen photographs of her work.

When I discussed what I wanted to achieve with the film with the special effects person, she asked me to actually purchase some of the make-up she would use. I thought this was an unusual request, but I followed her instructions. On set, she applied the make-up, plus a prosthetic, but after she applied it, she left the set. I was outside filming a different scene, when I noticed her drive past. She did a very nice job, but her leaving the set was quite unexpected. Here's how that became a huge liability. At the end of the day's shoot, the actor who had received the most make-up and eye prosthetic had a difficult time getting the make-up off. The special effects person had left very little instructions with my production assistant on how to remove the effects, but try as we might; those instructions were not very effective. It made for a tense time, at the end of a long shooting day, as a group of other actors, myself, and production assistants tried various ideas to help remove the prosthetic from the actor!

Former President Bill Clinton Voice-Over: Thousands of government-sponsored experiments did take place, at hospitals, universities, and military bases around our nation. Some were unethical, not only by today's standards, but by the standards of the time in which they were conducted. They failed both the test of our national values, and the test of humanity (Lakota, 2017).

Critical for the audience's understanding of racialized medicines was a scene which included the voice over of former President Clinton discussing racialized experiments. A typical trope of horror films is the epic failure of leadership to protect its citizens. Not forgetting that our government is sworn to protect its citizens, by sharing the voice of former President Clinton, I confirmed for the audience the truth of these kinds of



experiments, as well as the fact that many individuals had been left unprotected by the government.

This scene also sets up a somewhat lighter moment where the monster/ghosts come together in a field and greet each other, as ghosts. From there the audience moves from a lighter moment to one that is much more sinister in nature. In that scene, viewers can see from the actions and facial expressions that those who suffered through the experiments now want revenge.

### **Anatomy of a Scene #6, Death Scene Sequence**

In order to properly convey the reversed dynamics of the monster/ghosts and the human monster character, I created what I called the “Death Scene”. The “Death Scene” was created with a dramatic cacophony of sounds. In addition to the crackling thunder taking place off screen, the audience re-hears manic shrieks extracted from earlier in the film. These monstrous sounds were laid over some bizarre imagery, and Bias’ garbled words. The scene started out simply, but sonically it was multi-layered. There were non-diegetic sounds of wind, trees rustling and whispering. There were intermittent bursts of weird sounds and shifting musical notes. There were prominent sounds of a clock ticking, metallic scraping sounds, and a succession of bizarre screeches, and screams. These sounds, and music, were inserted to create a weird death sequence, and because the sounds were so odd, they also invoked a bit of the supernatural.

In the “Death Scene”, as in many other scenes, music played a prominent role. To project a climate of horror, the “Death Scene” was supported by a turbulence of pre-existent music that was stylistically rife with strong clashing dissonances and sonic

blasts. The end result created music that was a type of trauma. Prince (2009) shares that film allows viewers “to bear witness to trauma without actually visiting trauma upon them” (pp. 12-13). In fact, Aristotle (1961) opined that audiences go to the theatre for cathartic purposes. Aristotle (1961) goes further, sharing that audiences go to the theater in order to experience catastrophe, and so that they might feel pity and terror. With these things in mind, my film allowed the audience to visit, and witness, historical events, without the dark residual effects of true trauma.

To add to the tension of the “Death Scene”, and to spotlight the monster/ghosts ability to destroy humanity, I ensured that the dark, musical climaxes hit the mark with the edited, varied fast-cut visuals. As lovers of horror are aware, the threat of human annihilation has been rather typified within the genre. By focusing the audience’ attention on this previously established fear convention, grown strong by the human silhouette of vulnerability, I tapped into the audience’s sense of unease.

*The Colored Pill* varies thematically from other horror films because of my lack of gore and buckets of blood. Where I mirror other horror films, however, was in the pace and volume of music to ramp up of violence. Inserted into the “Death Scene” music were bits of fractured dialogue from the film, cut up into rapid-fire moments. These creative techniques were used to help establish violence, where in actuality, there was very little violence filmed.

*The Colored Pill* is a film about a pharmaceutical. It is a film about a race based pharmaceutical. It is about victims of those kinds of pharmaceuticals and experiments. It is also about the lack of acknowledgement that racism in medicine exists. Some of the

incidents, shown in the film, took place in the past. Some things are taking place today, as in the case of BiDiI®. Indeed, our past and our present are intimately and profoundly plaited together. That entwinement is shaped and made meaningful by not only our physical environment, but also by our symbolic, racial, social, cultural, and psychological consciousness. Thus, the gap between history and performance scholars twists and coils around a grievous gap existing between our present sense of history and our buried past.

The focus of this study aims to inform and build on a new foundation for social inquiry—using performance to increase knowledge about race based medicines and treatments. In chapter six, I examine audience viewers' reaction to the film, *The Colored Pill*. In the data collection phase of this chapter, I again called on witnessing through focus group interviews. In data analysis, I use a deductive coding approach, allowing the tenets of psychologist, William James McGuire's (1968, 1969, 1972, 1978, 1983, 1985, 1986) information processing method, to be integral to the examination of qualitative focus group dialogue and questionnaire responses.

## **Chapter Six. Fright-Fest Focus Groups**

### **Research Design and Method**

*“Do you mind if I turn on my recorder in case something brilliant happens”*

(W. Eugene Smith quoted in Stephenson, 2009, p. 14)?

*“The only thing more outrageous than using our faulty intellectual processes, including scientific inquiry, to arrive at a representation of reality is not to use them”*

(McGuire, 1985, pp. 584-585).

### **Introduction**

In 2014, anyone who watched the television news regularly learned that race crept its way into the well-publicized murders of African American Eric Garner and 12-year-old Tamir Rice. What is not widely known is the monstrous murders were recorded. In fact, they were filmed. As a result of those deaths, protests and outrage howled across our nation. Even though hard, tangible film evidence bespoke the series of events leading up to the murders, the film failed to compel grand juries to action, and consequently, failed to so much as indict the murderers.

With quiet precision, the murderers got off scot free, while the blood of Eric Garner and Tamir Rice ran like a river in the streets. We, Americans, are hip-deep in indifference. These are the moments when we all back away from the scene of the crime with that *yes-that’s-true-now-what’s-for-dinner* expression on our faces. Is it possible

that a film can turn the monster of *sullen indifference*, so prevalent in our land, into *difference*? Can a film educate the masses, and if so, how?

Of particular concern in this study is the question of whether a film performance can affect knowledge. Or, are the monsters of indifference, racism, and even history, having already overstepped their bounds, now too strong to corral?

As stated in prior chapters, in 2005 the FDA approved BiDil®, the first pharmaceutical created solely for African Americans. And while on its face, the medicine was designed to heal heart failure, in this study, I attribute its approval as a monstrous act. Why? I argue that in one fell swoop, race eased its way into medicine just as a ghost eases its way into an abandoned house. Although in this case, the abandoned house is our house—our house known as the United States—and the fractious *ghosts* came to kill, steal, and destroy a race of people who built the house. That house was built by a dark-skinned people whose rich African ancestry is noticeable in the kink of their hair, the darkness of their skin, and the lines of dignity etched across their faces. I am not so stubborn as to believe this group built the house alone. It was also built by other bodies of color—brown skinned, red skinned, yellow skinned, and white skinned.

Unfortunately, if the building of America stands for our mightiest dreams and ideals, so, too, do our failures. The disavowal of responsibility for some of America's citizens represents our ability to simultaneously exploit and ignore some of our very own. Instead of confronting what we have become, we often abandon our most vulnerable, at their greatest time of need. Just ask Tamir Rice and Eric Garner, victims to the bloody hands of injustice right in their own homes—the home they call *their* America.

Just as we are witnesses to the normalization of murder in this country, I fear we are also witnesses to the normalization of racially skewed pharmaceuticals. The wheels of the pharmaceutical machine grind away, even if what it grinds down to dust is equality in medicine. And, in the face of injustice, I see the urgency. I have to stand up to keep normalization from taking root. I must join the fight, even if it is impossible to win. These self-reflective views indicate both my personal vulnerabilities and my personal truths.

As a member of the African American community, where bodies and narratives have been situated in a racialized history, for this study I drew on storytelling as film performance. It is through this context that I argue that film performance can be utilized as both a theoretical and methodological tool. For this study, I enter the arena of debate, calling into question the methodological use of film to represent the past, while at the same time, I present a work of history that offers a new paradigm on racially skewed drugs like BiDil®. How did race get mixed up with medicine? Pharmacogenomics.

Pharmacogenomics is the study of how genes that represent differences can impact drug responses. In the case of BiDil®, and other therapies like it, race crept along the edges of the swamps, past the dry river banks, over the crisp, glistening snows, beneath the buffalo bones until it submerged itself in the safe, fertile ground of medicine where it could live and breathe undetected. It was not hard to do. After all, in this country, science has always been king. No one else can excavate huge vats of medical knowledge, and then vault it all away in underground chambers. Only a fool or someone

with a very large sword would challenge the scientific king, but perhaps I am that fool. Perhaps I am the very large sword.

Egalité, Ozdemir, and Gödard (2007) provided research on the double-edged sword of linking race to the science of pharmacogenomics, at the same time that the pharmaceutical industry ran head first toward race-based screenings and race specific tools for diagnosis and treatments. It seems that on these murky, medical grounds, the research behind the approval of BiDil® excavated differences from the *racial* part of our DNA.

At the inception of this study, I wrote, produced, and directed an innovative, issue- and knowledge-based film performance—that resulted in the 70-minute film, *The Colored Pill*. Question: What were my allegations in creating this film? Answer: That the secret history of race based medicines must be revealed. It is not just important to reveal the histories behind race based medicines in our past, though I cover many of those instances in the film, I believed it was also important to shed light on race based medicines in our present, and very likely to be approved in our future.

The creation of *The Colored Pill* film was an absolutely essential part of this study. In creating a performance, I visually enhanced my research study with a film—something that serves as a woman-made, cultural artifact for this field of inquiry. Here, I call my film a *cultural artifact* as I use the film as a kind of meaning-making tool that would provide some insight into the unholyest of unions of race, medicine, and inequality. In my research, the intertwining of race and health broke into my curiosity, but since most people in this country do not organize their worlds around these assumptions, I

hoped the creation of a cultural artifact might help other individuals see the associations I did. My use of a film performance as a cultural artifact points to the specific way in which I chose to tell the story of race based medicines.

In order to better understand knowledge about race based medicines, my aim was to collect knowledge level data about race based medicines, after a shared viewing of *The Colored Pill* film. While the creation of a film to be viewed was clearly the first half of this aim, the second half was just as important. The second half of my aim was a close examination of knowledge increases, on the topic of racialized members, from viewing audience members. In order to do so, I needed to get feedback and conduct interviews with the viewing audience to determine whether, after screening the film, it had any effect on knowledge. Evidence of the entertainment value of films has been documented. While many feel that issue-based film performances can impact public awareness on a variety of topics, little research has sought to measure this impact. Through film performance, my aim was to help viewers peer into the dark history and look into the face of the monster, in this case, the history of race specific medicines. Just as important to me was the examination of the impact of the film, from a stance of knowledge building. To do that, I needed to examine audience viewers' reactions (knowledge) to the film.

When the FDA approved BiDil® based on so-called biological differences, they were not exactly a poison peddler, but I felt they poisoned the remedy. One of the monsters in the medicine cabinet has been the raising of public expectation from the medical industry, about the merits of race based medicines, while at the same time the industry de-emphasizes the history of racialized medicine. This kind of medical



manipulation—particularly as it relates to racialized pharmaceutical experiments—existed in the past, as it does today. In the past, individuals were told by scientists, that Blacks were inferior to Whites, and in fact, the basic biological frame of Blacks was different than Whites. At the same time, the same medical industry performed secret guinea-pig type experiments on Blacks, knowing all along that those results would benefit Whites. If the bodies of Blacks were completely different, as scientists professed, then how could medical experiments performed on Blacks, help Whites?

Fast forward to 2005, when the FDA approved the first race based drug for African Americans, but the clinical trials *only* tested the drug on African Americans. If only African American patients were tested, how do we know the drug would not have helped others?

More than that, on the surface, a race specific pharmaceutical cleverly hides its scientific racism. In the case of BiDil®, the medicine actually helped mortality rates of African American heart failure patients. However, when one presses in, when we look at the fact that drugs tested on Whites are approved for all people, in a one-size-fits-all type basis, but a drug tested on African Americans is approved *only* for African Americans, the medical fallacy comes into clear view.

If the FDA tended to lean more toward the belief that an individual's race is biological—that is, determined by genetic distinctions—then they probably saw nothing wrong with approving a pharmaceutical based on race. If the FDA, like the millions of social scientists in this country who are against racial targeting, had seen race as a social construct, then they might have questioned prescribing a drug based on race. They might

have questioned it because in doing so, it ignores other factors like social and environmental influences and lifestyle—which affect health. There was a simple remedy the FDA could have done. Instead of allowing for one study to test African Americans, another to test Whites, another to test Asians, Hispanics, Arabs, etc., the FDA could require studies be more uniformly diverse across the board. If the FDA did this, they would not poison any remedy for any pharmaceutical, but instead, would ensure that clinical trials are more uniform by seeing to it that many races are tested. Further, if the FDA adopted this as their policy, in clinical trials, race would be considered one factor, but just one of many factors. The end result of this practice would result in no longer biologizing race, and in fact, de-accentuate race in clinical trials.

For this qualitative study, I was interested in what other self-identified African Americans, being the object of affection for race specific drugs like BiDil®, felt about the remedy of biologizing race. If I was going to uncover the thoughts and revelations of self-identified African Americans about racialized drugs and treatments, I needed to create a safe space to have that discourse. The first space that came to mind was focus groups. I believed the discourse component, inherent in focus group research, made for an appropriate tool of data collection for my call for social awareness and education. This call was embedded within my epistemological research question.

The very nature of focus groups lends itself naturally to qualitative, interview research. Data from focus groups is often not the type of information that can be readily gleaned solely from surveys or questionnaires. While surveys and questionnaires, also

used in this study, can provide useful information, they cannot always elicit the rich, qualitative data that flows from focus group discourse.

### **Qualitative Research**

I was drawn to qualitative inquiry as an approach to this study because it prioritizes social interactions. For this study, social interactions were critically important. I was most interested in what audience viewers thought about medicine soaked in the odorous river waters of difference. To study difference, specifically medical, racialized difference, I chose a qualitative inquiry that would deepen my understanding of how a film performance could externalize the bread and butter of a difficult part of our history—a history that demonized racial difference.

Qualitative research has been called upon as a strategy of social change (Denzin & Lincoln, 1994). Gaventa (1980) shared the film production process itself can be important for activist groups. My plan for my film performance would result in the creation of a qualitative, meaning-making device, and thus, a fresh and new method for knowledge. Perhaps it is the social change activist in me that placed emphasis on the role of film, and its potential impact. After all, the ultimate goal of the film, *The Colored Pill*, was for social change through education. Perhaps I was interested in creating a film that would advance an alternate public discourse about history. Perhaps I wanted to bring marginalized voices into dominant public discourse. Performance is a powerful communication instrument. As epistemology; film performance serves as a tool for individual and communal meaning-making. It is an excellent way for audiences to make sense out of social issues. As a pedagogical tool, film performance provides a unique

perspective for connections between not only the subject and the audience, but also between the past and the present. For all of these reasons, it was always my intention to use qualitative research to capture and mine the social impact of film, not just as a source of entertainment, but as a way to stand on the frontlines of knowledge generation.

In this chapter, I take a qualitative approach to the examination of the impact of *The Colored Pill*—a film that, when you strip everything else away, is a performance about pharmacogenomics, yet the structure for this study is indeed multi-faceted. Partially centered in pharmacogenomics, this study is also centered in a specific pharmaceutical product known as BiDil®. Yet, the overall approach to this study also has a performance lens.

Theoretically, this research project adds to the development of performance through the critical investigation of film, not just as a cultural artifact, but as performance history. Merrill (2006) declares, “Performance history ... like other forms of historicizing, involves the performative act of telling a story—literally calling it into being” (p. 65). Davis (1988) sees films involving performance history as, “those having as their central plot documentable events, such as a person’s life or a war or revolution, and those with a fictional plot but with a historical setting intrinsic to the action” (p. 270).

In previous chapters, I situated performance history films in monstrosity, and in the horror genre. Performance scholarship in the cold chill of monstrosity exists, yet very little research delves into the effectiveness of the horror genre. More scholarship focuses on horrors’ goose-bump raising scares, but very little in its deep ability to enlighten, to

raise consciousness, and to raise awareness. Even fewer delve into scholarship on horror's ability to raise knowledge about racialized medicine.

Admittedly, the concept of race based pharmaceuticals is not widely known. Research exists about race based medicines in scientific communities, but although racialized drugs are most prevalent in marginalized communities, intercultural research is surprisingly thin. There is a scarcity of intercultural research that focuses on knowledge and beliefs about racialized drugs, held by communities of color. Yet, I believe future acceptance of racialized drugs should rest on what the public, including communities of color, know about these types of drugs. Unfortunately, history shows that few communities of color are even familiar with the full history of racialized drugs.

### **Contextual Frame**

Since 2005, when BiDil® was approved, the public has been exposed to very little mass media about its history, or about the history of other race specific drugs and treatments. If the intent in drugs like BiDil® was simply to save African American lives, then transparency about the drug and about the drugs' controversial evolution should be freely given. Yet, when I asked African Americans that I knew, what they knew about BiDil®, I could not find a single person that had even heard of the drug. That being the case, I became interested in researching how much, other individuals of color, knew about BiDil® or about other remedies like BiDil®. To fan the flame on this topic, I chose to employ a film media.

Knowing that we live in a media-saturated world, the image-making qualities of film are a fundamental part of our culture. After all, films archive history, at the same

time they reflect it. Most would agree, we often know what we know because of a film we have watched. Burgoyne (2007) reasons that, “Film, better than any other medium, can provide a vivid experience and a powerful emotional relationship to a world that is wholly unfamiliar” (p. 553). With this information, I embarked on a mass media driven, film performance study.

Key works of scholarship, from a great variety of disciplines, have shown the media as an important source of information and communication (Scheufele & Tewksbury, 2007; Zaller, 1992). Mass communication research scholars have examined media-driven messages and social reality (Hall, 1980; 1993; Lesage, 1985; Monaco, 2009; Rose 2012). McGuire’s (1969) research examined attitude change work and the study of mass communication. Media coverage has also proven to increase the importance of varied topics in the minds of the public (Fiske, 1987; Gerbner, Gross, Morgan & Signorielli, 1980; McCombs & Shaw, 1972). The mass media has served as a critical source for information about scientific studies as well as new medical technologies (Loo, Byrne, Hardin, Castro & Fisher, 1998; Moynihan et al., 2000; National Health Council, 1997; Sitthe-amorn & Ngamvithyapongse, 1998; Zaller, 1992). Yet with all the research which shows that knowledge and attitudes on a variety of topics can be shaped through the mass media, a scarcity of research examines the media and race based medicine.

Marco’s (2010) study found there were racial differences in attitudes about race based medicines, with African American respondents being more distrustful than White respondents. No surprise there, given the history of abuses in medicine within the African

American community. Bevan et al. (2003) shared that African American, Hispanic, and multi-racial focus group participants were, on average, *moderate to highly suspicious* about drugs specifically designed for African Americans. The Bevan et al. (2003) study found that even European Americans were *slightly suspicious* of race targeted drugs.

Yet, physicians *are* prescribing race targeted, BiDil®. We know this because evidence from board-certified members of the American Association of Black Cardiologists (ABC), indicate the majority of physicians are prescribing BiDil® to their Black patients (Akinniyi & Payne, 2011). I have absolutely no issues with physicians prescribing BiDil, if they do so with no regard to the race of the patient. Disturbing to me are Lynch and Dubriwny's (2006) research findings that indicate, despite suspicious attitudes regarding race based medicines, African American and Hispanics would use a drug with race specific indications, if prescribed. Even more disturbing is the fact that even though African Americans tend to be suspicious of race targeted drugs, they would still take them, if prescribed by their physicians. Because of these givens, I had grave concerns about the fact that a drug like BiDil® would be prescribed to individuals who possess very little to no knowledge about it. Coupled with those concerns, I believe it to be quite unlikely that physicians, who would prescribe BiDil®, would also take the time to explain the drugs' long and disturbing history, to their patients of color. I believe it immensely possible that these patients might simply take the drug without knowing its history. For me, the results of this create a large, relatively uninformed population of patients, who may know little of the *race-is-biological* component embedded within the drug they are ingesting. Desiring to add to the scholarship of informing the public about

racialized medicines, I set off to do something about elevating knowledge levels by writing, and then producing an informative, history-driven film about BiDil® and other treatments similar to it.

In the upcoming research design section of this chapter, I usher in reflections from scholars Dwight Conquergood and D. Soyini Madison, and explain how they informed my data collection work using performance and filmmaking as a tool for socially constructed knowledge. Like Conquergood and Madison, I situated and contextualized this study using performance-centered pedagogy as a form of knowledge. In so doing, I opened the space between analysis and action, and showed how I came to bead together performance along with audience reactions, to form a critical analysis of this study.

### **Research Design Work: Reflections from Dr. Dwight Conquergood and Dr. D. Soyini Madison**

Exemplary scholars in their own right, Dr. D. Soyini Madison and Dr. Dwight Conquergood provided me with unique insights and a commitment to performance that assisted my data collection and analysis work. Emulating both of their scholarship, I sought to honor and document marginalized voices, both in the design of my film, as well as in my focus group research.

Guided by Dwight Conquergood, my study adopts the praxis of film performance as a visual instrument of research. My film also creates a dialogical performance—a way to create a respectful relationship with the other, in this case African Americans, through performance. Conquergood (1985) called on film as an instrument of research when he created, *Between Two Worlds: The Hmong Shaman in America*. Again, Conquergood



(1991) adopted film as a visual instrument of research in, *The Heart Broken in Half*.

Using film data as research, he examined and preserved cultural identities that otherwise would have been ignored, or worse, would have been forgotten. Creating a film for analysis is directly related to the scholarship of Conquergood (2002) when he argued for non-written forms of knowledge rather than privileging the written word.

D. Soyini Madison adopts performance as a tool to amplify marginalized voices, embroidering critical pedagogy with praxis. Madison (1993) shares, “Performance helps me see. It illuminates like good theory... Like good theory, performance is a blur of meaning, language, and a bit of pain” (p. 109). In my data collection, I was inspired by D. Soyini Madison, in that performance, for me, was not only an approach to inquiry, but rather a type of collaborative meaning-making. At the same time, my data collection was also inspired by Dwight Conquergood’s (1989, 1992) themes of performance as change, and *poesis*, performance as meaning-making. That being the case, I built into my research design, performance as a tool of meaning-making.

As epistemology; film performance is an approach to meaning-making. Meaning emerges from the film performance itself. In fact, meaning-making was so critical to this study, that in my data analysis, coding was chosen to support a particular type of meaning-making, namely the elevation of knowledge about the victims of racialized medicine. While I cannot pay those victims back for the racial atrocities done to them, I can pay it forward. Why? Because I stand on the shoulders of those ancestors—victims of racial experiments whose lives were not seemed fit enough to be written about in the margins of textbooks. I pay it forward by creating a film performance exposing racialized

medicine, and shedding light on the experiences of those who had the indignation of coming closest to it.

Conquergood's (2002b) research both encouraged and served as a challenge for me to reach beyond the text, for a new method of analysis about ways of knowing. I agreed with Conquergood when he exposed the limitations of *textualism* as the sole way of advancing and transferring knowledge. Clearly, both in designing my film, and in designing my research methods, I followed the lead of scholars Dwight Conquergood and D. Soyini Madison as well as their views on filmmaking and performance. I do not make the claim that film performance is the *only* way to anchor knowledge in practice, as Conquergood wrote about often, but I argue that it is *a* good method.

The research question for this study is grounded in the literature review performed in a previous chapter, where I argue four primary areas of film scholarship: literature on history films from a historian perspective, the impact of history films on knowledge, history film performance from a communication perspective, and history film performance about race based medicines. This section aims to emphasize the research question that guides this study, by examining the transfer of knowledge from film performance, *The Colored Pill*, to focus group participants. The research question (RQ) question for this study is: How does a film performance function to affect knowledge of race based medicines? Clearly, with that question in the forefront, there are two components to my research question—film performance and race based medicines. However, since the drug BiDil®, primarily targets African Americans, and my film performance also primarily targets the same racial group, I have included *African*

*Americans* as a third, *implied* element of analysis. That being the case, I needed to ensure that, in my methods, all three elements were examined in order to adequately answer the research question. By examining these three elements—film performance, race based medicines, and African Americans—I add the qualities of coherence and compatibility to the design of my study.

Focusing on both coherence and compatibility in my research design, I asked myself why I was interested in collecting and analyzing the data in the manner in which I proposed. I also asked myself, what I hoped to learn by doing so. Only after answering these questions, was I ready to consider how I would measure my research.

Finally, in the design of my research question, there was one additional step I needed to consider. That step was measurement. In the early days of my research, I sat and considered all the necessary ingredients for my study. At that time it became clear to me that in using film performance as a visual method of inquiry, audience feedback would also need to serve as my design partner. In the next section, I introduce the significance of focus group interviews as a design and method of qualitative research. In addition to discussing the dynamics of focus groups, I take a close and thorough exploration of the kinds of insightful and detailed information that can be provided through focus group discourse. I knew that audience feedback would serve as a fantastic tool of measurement for this study. With that decided, I researched focus groups for the all-important audience feedback I needed. I knew the reactions and responses from focus groups would serve as indicators of the transfer of knowledge.

## **Research Design: Design Strategy**

In a previous chapter, I analyzed the creation of the film, *The Colored Pill*, as a monstrous cultural artifact. To be clear, the film I wrote, produced, and directed does not represent the data to be collected. Rather, the actual data is discourse from focus group interviews (transcript data) about *The Colored Pill*. Therefore, the units of analysis for this study are the words, phrases, sentences, and utterances extracted from focus group interviews, all of which indicate intensified knowledge of audience viewers about the drug BiDil®.

### **Focus Groups**

To measure the films' ability to affect knowledge, I chose to examine interview discourse and group questionnaire responses through focus groups. There are several reasons why focus groups were deemed the most appropriate method of data collection. First, focus group interactions are an excellent opportunity to explore film audiences' views and insights. Morgan (1988) shares the hallmark of focus groups are, "the explicit use of the group interaction to produce data and insights that would be less accessible without the interaction found in a group" (p. 12). Second, Morgan (2006) discussed focus groups this way: "The best focus groups ... provide data on *what* the participants think but also explicit insights into *why* they think the way they do" (p. 123). Third, Tracy (2013) provided additional insight when she shared focus groups "are well poised for learning how certain groups react to a similar issue or shared experience" (p. 169). With all of this rich, focus group information in hand, I knew that my focus groups would serve as an excellent means of inquiry and a critical component of my research design.

### **What are Focus Groups?**

Focus groups are, “carefully planned series of discussions designed to obtain perceptions on a defined area of interest in a permissive, nonthreatening environment” (Krueger & Casey, 2009, p. 2). Historically, the communication discipline first used focus groups in the 1940s to examine the effects of film and television (Merton, Fiske, & Kendall, 1956). Brocato, Gentile, Laczmak, Maier and Ji-Song (2010) provided research on how focus groups have been used to study the potential social effects of television violence on children. Woelders (2010) used focus groups in an inquiry of how historically themed films could be used to encourage students to compare historical accounts. McCool, Cameron, Petrie (2001) used focus groups to research how adolescents interpret and decode images of smoking in films.

Marczak and Sewell (2007) define focus groups as, “a group of interacting individuals having some common interest or characteristics, brought together by a moderator, who uses the group and its interaction as a way to gain information about a specific or focused issue” (para. 1). Clearly, focus groups are dynamic group dialogues. In focus groups, the interactions can be quick, but the ideas can be long, yet critical to the overall research. Krueger (1995) states, “Focus group research has gained increased acceptability within academic institutions” (p. 525). It was the fact that focus groups have the ability to provoke thought and raise awareness, which made them particularly intriguing for this study. I was also interested in focus groups’ ability to expand current beliefs about certain topics.

Just as all things in life, focus groups are not without their share of imperfections. When making data collection decisions for this study, I considered several types of research to serve the goal of my research question. While I ultimately decided on focus groups as a method of data collection, I only came to this view after balancing its strengths against its weaknesses.

### **Focus Group Strengths and Weaknesses**

Focus groups were chosen because among other methods, they provide direct observables to test the feasibility of my using a film performance as a tool to provoke thought within a group, while elevating knowledge. Tracy (2013) shares, “Focus groups are well poised for learning how certain groups react to a similar issue or shared experience” (p. 169). Therefore, a tremendous strength in using focus groups is the benefit of group dynamics, meaning various group reactions and viewpoints can be given.

An additional strength of focus groups is the research in existence about how best to use this method in films. Wilkins (2009) used focus groups to examine the portrayal of Arab communities in action-adventure films. Hughey (2014) used focus groups in his study of racial depictions in films where a White male savior is incorporated into the narrative. For this study, I was immensely interested in what communities of color know about racially targeted medicines. Within the context of this study, my results will therefore, not be considered representative of views held by the general population. Rather, my results are indicative of thoughts held primarily by communities of color. By that I mean, the implementation of focus groups within particular communities is helpful in becoming aware of rarely heard, minority thoughts and views.

Krueger and Casey (2000) share that focus groups are an inexpensive, yet efficient, way to obtain participant data. In this connection, given my need for an inexpensive and efficient method, my study gathered data from accessible participants who live and dwell in the easily accessible Denver metropolitan area.

As a process, focus groups are perceived by participants as non-threatening. In my study, in order to obtain honest responses and emotions, it was vital that my participants felt safe and comfortable in sharing their thoughts and beliefs. By creating focus groups, I was able to maintain a non-threatening environment for excellent group dynamics among my participants.

While dynamics among participants is critical, I must acknowledge that it also serves as a focus group weakness. By this I mean that in focus groups, certain members become unduly influenced by the responses of others. Zeller (1993b) reveals that this can result in members agreeing with others' responses, rather than holding their ground on their own. I observed this when, during my study, one member, who previously held a certain opinion, unexpectedly changed that opinion to divert to a dominant member. I believe if I had held one-on-one interviews, the first member would have maintained their position on that particular topic. Instead, they caved to the opinion of a stronger focus group member.

### **Content-Oriented Approach to Focus Groups**

While a conversation-oriented approach is often linked to studies involving focus groups, I chose a content-oriented approach. Hugely relevant to my study goals, was the need to focus my participant's attention to the film content. For this reason, a content-

oriented approach was the most salient. Unlike a conversation-oriented approach, a content-oriented approach focuses more on one topic. Macnaghten and Myers (2004) compare content-oriented and conversation-oriented approaches, sharing that with content-oriented, researchers are interested in “*what* was said” versus in the conversation-oriented approach; researchers concentrate on “*how* it was said” (p. 74). While both approaches are sound and quite useful, I tend to think of a content-oriented approach as a focus on the cake, while a conversation-oriented approach as a focus on the icing. For my study, selecting a content-oriented approach allowed me to close the gap between *what* my participants had to say about racially skewed medicine, the content, as opposed to *how* they said it, the conversation.

Having now discussed my data design, in the next section, I move on to my method of data collection. Here, I discuss the selection criteria I utilized for focus group participants, the actual break down of my group, as well as the protection of human participants. The next section will also cover my role as moderator, my assistants, the focus group venue, as well as the interview protocol.

### **Method of Data Collection**

The data for this qualitative study was gathered from semi-structured, focus group interviews. The focus group members were primarily made up of members from the African American community, and/or other communities of color. To answer the research question for this study, my in-depth focus group interviews were supplemented with questionnaires, which served as additional research instruments. DiCicco-Bloom and Crabtree (2006) assert that, “Semi-structured in-depth interviews are the most widely



used interviewing format for qualitative research” (p. 314). Quite a bit of focus group scholarship has studied interviews with filmmakers, marketing, and exhibition (Cunningham, 2005; Edwards & Powers, 2013; Jolliffe & Zinnes, 2012; Levin, 1971; Stubbs, 2002; Tobias, 1998). Additionally, a good deal of filmmaking research includes examinations of semi-structured interview methods, bookmarked by a series of open-ended questions and answers.

In the next section, I illustrate how, centered in Glaser and Strauss’ (1967) grounded-theory principles, my data collection followed a two-part framework of closed-ended questionnaires, in tandem with open-ended, semi-structured focus group interviews. Included in this discussion is the process of audio recordings I used to sop up thoughts of the focus group participants. First, I will highlight my process of selecting participants for this study.

### **Participant Selection Criteria**

Krueger and Casey (2000) suggest recruiting participants by similar characteristics such as age, income, education, gender, culture or language. The focus groups for my study were recruited primarily from groups of self-identified African American participants. These participants were selected because I knew that, with their racial and social identification, they could speak to similar lived experiences. *“Tell someone I’m here”* (Galeano, 1992, p. 72). *“I am here in the world among you”* (Madison, 1998, p. 173). I specifically identified the African American demographic as my primary target audience because the drug, BiDil® specifically targeted this audience. I also identified African Americans because I knew they could speak to racialized issues

and experiences, rarely publically exposed, important to my topic. My secondary audience was other members of color.

An important study indicates that racial and ethnic minorities tend to describe themselves in racial or ethnic terms (McGuire, McGuire, Child, & Fujioka, 1978). Research further suggests that members of minority groups identify more strongly with their own groups, than members of majority groups (Brewer, 1991; Huddy, 2002, Leonard, Mehra, & Katerberg, 2007; Sidanius, Levin, van Laar, & Sears, 2008). With a shared history, African American and other members of color as focus group participants would be well positioned to provide their views on the subject of racialized medicine, particularly those pharmaceuticals targeted specifically to that community.

As I made decisions about the composition of potential focus groups, it was important to place in the forefront the need for a mix of perspectives from individuals from a variety of racial demographics. While African Americans served as my primary focus group audience, at the same time, I was also interested in being inclusive. I did not want to devolve into group think by only hearing from one community. Instead, I empowered the views from members of other communities of color. There is an African saying that goes, *If you want to go fast, go alone, but if you want to go far, go together.* To that end, my highest aspiration for focus group participants was to go far. I built a bridge across several communities of color, bringing a variety of other marginalized voices together. That being the case, my participants needed to be individuals who primarily identify as a member of a community of color. Krueger and Casey (2000) indicate that focus groups are more effective when participants share key characteristics.

Hesse-Biber (2017) opine, “focus groups are an important tool for accessing the experiences and attitudes of marginalized and minority groups, including racial or ethnic minorities” (p. 151.) To adequately promote focus group conversations and speak to my research question (which paves the way for additional research on BiDil® and other race based drugs), an overrepresentation of African, Asian, and Latina/o Americans participants were recruited, as this study concerns itself with race based drugs targeted specifically at populations of color. I am happy to report, that I realized my motivation for this kind of focus group. The focus groups I banded together for this study, were made up primarily of African Americans, but also included voices from several other races and ethnicities.

### **Participant Recruitment**

Following Institutional Review Board (IRB) approval, I wrote, directed, and produced *The Colored Pill*. It was my belief that an awesome way to research my inquiry was to build a film performance that would give voice to victims of racialized medicine and would raise knowledge about instances of racialized medicine, past and present. In a previous chapter I describe, at length, all of the aesthetics involved with film production—casting, lighting, working with a cinematographer, production crew including drone operators, and location scouting, to name a few. All pre- and post-production decisions were made by me in the creation of the film, *The Colored Pill*. This film was supplemented by significant post-production work in sound design, Foley, and special effects. The following are the procedures I utilized for the recruitment of my focus group participants, after post-production.

Since a significant element for this study involved screening *The Colored Pill*, careful selection of potential focus group participants was crucial. Added to that, the focus group audience I sought was not easy to find because they needed to meet specific demographic and psychographic standards. As a psychographic segmentation, my audience members needed to have a shared interest in items related to race, and specifically, related to racialized medicine. With these ingredients in mind, it seemed to me that targeting a cross-ethnic demographic (emphasizing the African American demographic) made the most sense. Since my sample was determined by racial/ethnic demographics, I chose snowball sampling.

Belonging to a local church, with a predominance of African American and other communities of color; I first identified participants who I believed to be great candidates for participation. I approached a few individuals that I knew, from the church. In addition, I asked key church members to help me with recruitment by suggesting friends, acquaintances, and/or family members who might be interested in my study of race targeted drugs.

I also belong to a few community groups, with a predominance of African American and other ethnic minorities, in their membership. There, I again asked key members to help me recruit colleagues and friends from within the group. As a result of these efforts, I was able to identify potential participants.

After receiving permission from decision makers in churches and community groups, I was allowed to place an Open Letter of Invitation (Appendix A) within their offices or common areas. In some cases, names, phone numbers, and/or email addresses

of potential participants were provided by church or community members. When that happened, I emailed my letter of invitation to those potential participants.

When approaching participants, either by myself or through church/community leaders, they were told the topic being studied was a focus group about race based medicine. They were always quickly told that a requirement to join the focus groups was an agreement to being audio taped, and that without that agreement, they could not participate. Participants were also informed that a signed, informed consent was a requirement and that again, without that signature, they could not participate.

Since my focus groups were accessed from community groups and churches, many of my participants knew each other. While some researchers believe focus participants should not know each other, there are many environments and communities where this is difficult to create. Community groups and churches are examples of environments where individuals are normally already acquainted and thus, already cooperative with each other. Though previous acquaintances existed in my study, which created some side conversations, that fact had minimal risk to my research content.

I made the determination that minors, under the age of 18 years, could not be permitted to participate. I made that age limitation due to the overall topic, the time span of the film, some of the violent depictions in the film, as well as the all-important discourse that would follow the screening. I placed no restrictions on family income or educational levels of participants. There were no additional incentives/ rewards for participating in the focus group offered or implied. No participant was harmed in, or as a result of, this research.

Four to six participants were planned to serve in every focus group. Hansen and Machin (2019) report, “Where focus groups form a central and more substantive part of the data collection of a study, it would generally be difficult to justify fewer than six groups” (p. 231). I originally planned to attract four to 12 focus groups. My rationale in selecting this number of groups is that after this range was accomplished, research indicates the data can become so saturated that minimal new information emerges (Zeller, 1993).

Several viewpoints exist regarding the optimal time frame length of focus group meetings. In keeping with scholars like Morgan (1997) and Vaughn et al. (1996), I originally planned for each focus group to last between one and two hours. Schmidt (2001) advocated for focus group sessions that lasted from two to three hours. During planning, I could not imagine that I would ever need more than two hours. In the end, my focus group sessions lasted longer than two hours. Accounting for the pre- and post-questionnaires, the screening of my film, and an open discussion where participants could freely express themselves, each of my focus group interviews lasted approximately 2-1/2 hours to three hours.

Participants for this study ranged from 18 to 69 years of age. From November, 2018 through December, 2018, a total of 38 individuals agreed to participate in one of eight focus groups. Interviews took place at community/church centers, as well as in private residences

### **Protection of Human Participants**

Prior to the start of focus group interviews, a proposal was submitted to and approved by the Institutional Review Board for the Protection of Human Subjects in Research (IRB).

Before each focus group, each participant signed written informed consent documents (Appendix B). The signed informed consent signified their willingness to participate in the study, their acknowledgement that the interviews would be audio recorded, and their approval for focus group data to be collected. The consent also indicated the participants' knowledge of procedures regarding confidentiality of data collected.

Participants were informed of identified risks, as a part of the study, which might have included emotional discomfort from answering questionnaire or interview questions. Participants were told that the probability of harm and discomfort from those identified risks was not greater than those encountered in daily life.

Under the ethics of working closely with participants, I ensured that each was treated with respect at all times. During focus group sessions, as the moderator, I avoided taking one participants' side over another, in order to mitigate additional ethical concerns. The privacy of participants was protected when I analyzed and reported the data for this study. In my data collection and analysis, I referred to participants only by identifying number. Within the study, confidentiality was preserved in the research instrument, as no individuals' response was shared with their names or identifying markers on the written questionnaires.

Additional information on the actual handling of the questionnaire instrument, focus group interview transcript, and focus group data is contained below in the Data Handling section of this study.

### **Role of Moderator**

During the focus groups, not only was I present, I also assumed the neutral role of moderator. Wimmer and Dominick (1983) venture that the moderator leads respondents in, “a relatively free discussion about the topic under consideration” (p. 100). As the moderator, I carried out the format for each of my focus group interviews in a manner that was predesigned in my focus group protocol (Appendix E). I tasked myself with keeping the participants on topic. I also did all I could to enliven the conversation while nudging participants to share their thoughts, opinions, and emotions.

There was a time or two when I experienced challenges managing the groups’ dynamics. This was particularly challenging when dominant speakers emerged, because I had made up my mind, in advance, that I would not act as the group *supervisor*. Instead, I adopted more of a referee position—a position where I sought to find a medium ground between views. On the challenge of managing group dynamics, Babbie (2010) shares:

Controlling the dynamic within the group is a major challenge. Letting one interviewee dominate the focus group interview reduces the likelihood that the other subjects will express themselves. This can generate the problem of group conformity or group think, which is the tendency for people in a group to conform to the opinions and decisions of the most outspoken members of the group. (p. 323)

There were certainly those times, when one member of the group dominated the others. Honestly, I seldom had to adopt the role of referee, but there were those moments when the group spiraled toward being a bit out of control. Luckily, those moments were



fleeting. In fact, I thankfully, never had a single time when the group went completely off the rails. Without that to be concerned about, I could focus on listening closely to my participants so I could determine whether each of my questions was being sufficiently answered. I also listened closely so I could determine when a follow-up question or probe (also included in my Interview Protocol) might be called for.

Adopting beliefs shared by D. Soyini Madison, as the moderator, I explained to the participants that I would co-perform with them, rather than act as a participant-observer. Though I co-performed with the participants, I did not perform as a focus group primary speaker. Rather, my role as moderator was to honor and coax my participants to interact and enter into lively discourse primarily with one another.

### **Role of Assistants**

Since I served in the role of moderator, I pre-arranged to have two assistants—one to act as my technology assistant, and the other as a general focus group assistant. In the role of technology, that assistant helped manage the computer which contained the film. That particular assistant also maintained watch over the audio equipment. On the other hand, the general focus group assistant helped take field notes for me, helped me host the event, answered basic questions from participants, and performed all the duties which assisted the interview in moving along smoothly.

Both assistants arrived a little over one hour prior to the start of each focus group. They used this time to set up and check the functionality of all necessary equipment. Conversely, both assistants were the last to leave the event, staying with me, until well past the last focus group member left. They both helped me straighten up the room,

getting it back to the orderly condition it was in when we arrived. They also both helped me gather together blank forms, clean up debris, including pieces of paper or pens left behind in the venue.

### **Focus Group Venue**

It was important that I chose comfortable, informal, and accessible venue sites for each focus group. It follows that in doing so, my participants would be able to relax, comfortably screen the film, and have a productive discussion about the film afterward. The venue needed to be conducive for this kind of easy interaction. Critical to the venue selection, was consideration as to whether or not the environment was private enough to be conducive to discussions. The venue also needed to be quiet enough so that discussions would not be interrupted or overheard by others who were not participating in the study. Additionally, it was important that proper restroom facilities, including residential facilities, were clean, and in good, working order.

The venues I selected for my focus group sessions were community centers and individual residences. In selecting venues for my focus group research, I did not believe, as do some researchers, that focus groups could only be held in pre-established focus group facilities. The venues I secured were comfortable (in temperature and seating), and held in medium sized rooms that easily accommodated the number of invited participants. Each of my venues included large screens, adequate tables for writing, comfortable chairs for conversation and electrical outlets for computers and audio back-up systems.

The seating arrangement I chose to view the film was somewhat classroom style, with each chair facing the screen. However, during the discussion, I asked the participants to move their seating into something more circular, not always easy when there were only four chairs, so that each participant could easily face one another.

Since I wanted my participants to screen a film, I needed to situate my viewers in the most visceral moving-watching environment possible. This meant creating an environment to support and enhance both the image and the film sounds. It would have been cost prohibitive to bring movie-quality, over-sized screens to each venue. As a result, I was dependent on the screens located at each venue. In the end, I was very pleased with the large, flat screens and/or monitors already in place. That left me to focus on the all-important sound portion of the film.

In prior chapters, I discussed my views on *sound as monstrosity*, and even *music as monstrosity*. For me, these are specific and necessary acoustemological structures for the monstrous to come into being in a film. In order to have viewers ensconced in horror, the music of monstrosity needed to be robust. To enhance the haunted, embodied and disembodied sounds, I rented additional speakers, and hooked them up to existing television screens or monitors. In the end, I was very pleased with the sounds of monstrosity, which came through loud and clear, during each focus group screening.

### **Testing the Protocol**

A few weeks before the start of the first focus group interview, a convenience sample, made up of individuals who were demographically and psychographically similar as the study participants, tested my protocol. In a private residence, this test helped me

assess whether or not my recording device would clearly record a variety of voices in a medium-sized venue. In my test, I needed to find out just how far from the audio recording device, voices could easily be picked up. Plus, I made sure that my audio recorder would be sufficient for the interviews, before I spent additional funds investing in a second recorder, or different kind of recording unit. Happily, the recorder I already owned worked beautifully.

In the test protocol, there were other items I checked on. I asked my convenience sample participants whether or not anyone thought my interview questions were vague or unclear in any way. Additionally, I checked the flow of my questions, double checking for awkward gaps or unusual leaps in subject matter. All of this was done, to help ensure my questions could easily be answered on the days of the scheduled interviews.

Surprisingly, my Post-Awareness questionnaire revealed some concern my test participants had with one of my questions. The question asked participants whether they thought the film was a compelling and dramatic story. Some of those in my test group thought the word *compelling* might be misunderstood. They wondered if the definition of word was widely known, and expressed some concern about whether or not the average participant would be able to adequately apply that word to the concept of a film. In fact, a few of them suggested that I change the word all together, from *compelling* to *persuasive*; however, the vast majority of test members vehemently disagreed with that suggestion. That group felt the word *compelling* was one they typically hear being used to describe films. That group felt strong about the fact that if I switched the word *compelling* to *persuasive*, it would indicate to the viewers that the whole purpose of the

film was to persuade. They wondered if some members of the viewing audience might have a resistance to a film that sought to persuade them, one way or another.

I could see both points of view from my test group, so I asked them if they felt the words *captivating* or *engrossing* might suffice instead of the word, *compelling*. No one, on either side of the table, liked either of those replacement words. In the end, I left the original word, *compelling*, on the questionnaire. No one in the actual focus groups asked a single question about the word. Of course, that does not mean they did not wonder about it.

Also, in my test group, I brought bags of popcorn and bottles of water as snacks. For the actual interview, while I never planned to pass out hot hors d'oeuvres, I did plan on bringing popcorn, thinking it might enhance the comfort of film viewing. Unfortunately, by the end of the test night, the popcorn had made quite a mess in the living room of the person who had agreed to host the test screening. Many also left their opened, bottles of water. In some instances, they had even spilled the water onto the carpet. Naturally, I stayed and cleaned up the popcorn from their carpet, and picked up the bottles of water, but pretty quickly decided against bringing either snack to the actual focus group interviews.

Another item discovered in my test was about the time frame. It was my initial belief that the entire protocol would take 1-1/2 to 2 hours. That proved to be incorrect. In the test, time speedily ticked away like a Swiss watch. Both of my test groups took over two hours—one ended at nearly three hours, and the other ended just a smidge past three hours. Allowing for the very casual environment of the test, I still deduced that my actual

focus group interviews would last longer than my planned 1-1/2 hours to two hours.

While it was too late to change my Open Invitation Letter recruitment flyer (Appendix A), already in the hands of my potential participants, I was able to announce the change in the time frame, at the start of each focus group session. I made this time change announcement early on, in the event anyone who had signed up for the focus group simply did not have more time to give to the process. I did not want to just take more of their time, and then end the night with unhappy faces glaring at me like I was an infection. Nor did I want them to be silent as graves because they really needed to duck out sooner. Luckily, even after making the time change announcement, I did not lose any participants.

The final item I worked out actually took place well before the test protocol. That item was related to recording. Though I had originally planned to video and audio tape each interview, in the end I chose not to do both. As I thought about my research more closely, I must admit that I had some initial reservations about videotaping. After all, with videotaping, I would need to spend an inordinate amount of time setting up cameras to capture several different angles of the room. What would I do if, during the interview, one of my participants stood up, and walked outside of the camera frame? What would I do if, by accident, someone tripped over the loose wires and cables attached to the camera equipment? This could happen, even if the wires and cables were tapped down. Another concern I had was what if some of the participants began *playing to the camera*, or *hamming it up* because they were uber aware that they were being recorded. Might that kind of behavior skew my results?

In addition to concerns about cameras, I also had concerns about lightning, knowing that would be another element to be considered and possibly mitigated. Further, I was unsure of whether video recording the actual gestures and faces of my participants would enhance my research, or detract from it. Having a video tape would certainly make it easier to identify varied speakers in the group as they spoke, but at the same time, I knew that none of my focus groups would equal to more than six people talking at a time. How hard would it be to discern the voices of six people on an audio tape? I decided it would not be difficult at all.

In the end, I became more and more certain I would be able to adequately identify each participant in the interview, from just audio recording. That made the decision of videotaping, or not videotaping, fairly easy, but in the end, the final decision was ultimately made for me. As I began to prepare for the overall interview timeframe, I learned that not every member of my crew was available for every focus group session. Admittedly, my crew is quite small, but I would still need to schedule a couple of people to operate the cameras and set up tripods, and another two or three to handle the external audio equipment. Not knowing if I would have a full crew for each and every focus group session was problematic for me, to say the least. For that reason, I decided I did not want to risk having a crew to video tape *some* focus groups, while not being sure if I would have a crew to tape others. Doing so, would have made my focus group data lacking in the kind of consistency I needed.

For these reasons, I scrapped the entire plan to video record the interviews. Instead, I decided to rely solely on audio recording. In fact, I was able to scrap the idea of

video recording long before I ever scheduled my first interview session, and long before I posted my first Open Letter of Invitation.

### **Recording the Focus Groups**

The decision to just audio tape my focus group interviews ended up being an excellent one because it provided a critical verbatim record of what took place. Having a visual record of the focus groups would not have contributed much, but the audio record was greatly needed for the data analysis part of my study. Serving as the moderator of the groups, allowing the audio recorder to do its job, freed me up significantly from having to simultaneously moderate the discussions, while also being concerned about the camera.

The method I chose to aid me with audio recording was a small, yet efficient device known as a Zoom. The Zoom is a cassette voice recording that not only possesses excellent quality; it also is equipped with four tracks of simultaneous recording, plus a multi-directional microphone. That multi-directional microphone made the recorder particularly useful for recording focus group interviews that took place in medium-sized locations.

The good news with deciding to only go with audio recording is the audio recording device is much less cumbersome in size than the equipment associated with video recording. To perform the audio taping, I only needed to bring along my Zoom recorder—a piece of equipment that is smaller than the average-sized textbook. This made setting up my equipment, for each interview, a breeze. The actual placement of the recording device was always centralized to the group, and since the quality of my recorder is excellent, all of the voices in the interview were picked up and easily detected.



While I brought a back-up tape recorder, with batteries, to every focus group session, my back-up recorder was never used.

### **Focus Group Interview Protocol**

The full Focus Group Interview Protocol, including follow-up questions and probes, is included in Appendix E. The Protocol was designed so that I could prioritize and clarify information that I sought from focus groups. My Focus Group Interview Protocol grouped and reframed topic questions so as to create easy flowing discussions. The Protocol also helped me stay on top of questions that had been answered, as well as questions that had not yet been asked.

In creating the Protocol, I ruminated very deliberately about, and identified, how much time to allot for each topic. I also contemplated on how many questions could efficiently be asked in the timeframe. In designing the Protocol, I thought through a few follow-up probes. I used the probes to keep the discussion flowing smoothly, and to prevent awkward gaps. Examples of a few follow up probes I utilized were:

- Does anyone have a different experience?
- Can you tell me more about that?
- Does anyone have an example they would like to share?

What follows, is an overview of the steps I took in conducting the focus group interview. The day before the focus group session, I confirmed the date/time with the participants via email. With that, I planned for more participants than I actually needed, but that would still comfortably fit in my venue. I did this in the event that some participants faced unforeseen circumstances requiring them to either bow out, or become

a no show. In nearly every scheduled interview, there were a couple of people that were, in fact, no shows. I was happy I had adopted the policy of inviting more participants than I needed.

On the day of the interview, upon arrival to the chosen venue, I greeted and welcomed each of my focus group participants to the interview. Making small talk with the participants, I also introduced them to the venue host (where applicable), pointed out the restroom(s), and showed the participant to a seat. At that point, I made sure I handed each participant an Informed Consent Form (Appendix B), for their review and signature. I also handed them the first two questionnaires—Demographic questionnaire (Appendix C), and the Pre-Awareness survey (Appendix D). The Demographic questionnaire asked questions about their gender, ethnicity/race, age group, education, types of films watched, and number of independent films watched in the past year. The Pre-Awareness survey set the stage for uncovering participants' levels of awareness about race based drugs. Both questionnaires, represented by a finite set of questions, were administered by pen and paper.

After all of the participants were settled down in their seats, but before the start of the film performance, I got their attention and introduced myself and my assistants. I immediately thanked the host for allowing the interview to take place in their venue. I also thanked the participants for coming to the interview. I quickly announced the change in time frame from 1-1/2 to two hours, to approximately three hours, and allowed time for any participant that needed to leave due to the change in time. Luckily, no one left.

After this, I went around asking participants to introduce themselves. I pointed out bathroom location(s). After that, I presented an overview of what was to take place during the interview. I made it clear the interview session would be audio-recorded, and reiterated the requirement for each participant to sign an informed consent agreement. I spelled out how the foci of the day centered on the screening of the film. Additionally, I went over that the broader goal of the focus group was to explore race based medicines as a part of my dissertation research. I made known the value and great necessity of focus group reflections and insights, for my dissertation research. I explained how, following the screening, they would receive a break. After that, I described how I would guide them in a discussion. I explained all of the pre- and post- questionnaires, as well as the order of each questionnaire's presentation. After unraveling all of these things, I asked if the participants had any questions or concerns. If there were, I quickly addressed them. Then, I collected all of the signed, informed consent agreements, and picked up the initial questionnaires. When those were complete, I offered the participants a break before screening the film. At that point, I screened the film, watching it along with the participants.

After the film screening, I allowed participants a short break before distributing the next questionnaire. At the end of that break, I asked the participants to complete and hand in a Post-Awareness Survey (Appendix F). It should be noted that before completing the Post-Awareness Survey, many participants excitedly asked numerous questions about my research, the making of the film, my rationale in researching the subject, etc. In fact, there were so many questions posed by the participants at this point,

that it often took some doing to get them to just complete the Post-Awareness questionnaires *before* we began our discussion. After nudging the participants to complete their Post-Awareness questionnaires, I continued following the Focus Group Protocol and lead the participants through several discussion questions.

At this point, I guided the participants in a semi-structured question-and-answer formatted discussion about the film. The formatted discussions were developed out of literature on best practices for qualitative interview research, which noted how this approach allowed participants to elaborate a bit, while sharing their opinions. Following best practices, I allowed my participants to share their opinions and even to elaborate on their own personal experiences related to the topic.

The first topic I asked participants, in the interview portion, was about the film performance itself. Follow up questions to that were about the films' effectiveness, style, and/or message delivery. Basically, I was looking for general thoughts from the participants about the film. I carefully selected this first question as a relatively easy inquiry. I believe the first few questions in a focus group set the tone for upcoming discussions. With that first starter question being easy to answer, I knew it would encourage many participants to join the discussion. A few of the initial questions asked were:

- Did the film affect you? How/In what ways? These questions were *aesthetic merit* questions, which call into question the artistic value the participant placed on the film.

- How was race based medicines portrayed in the film? Was it portrayed fairly? Did you detect a bias? These particular questions were *interpretive* questions, designed to uncover the films' meaning, relevance, or significance to the viewers.
- How did this film help, in terms of providing insight on how participants might act if race based medicines are prescribed to themselves or members of their families? This question asked participants to take a more *critical* look at the film. The question was designed to shift the viewers beyond just *what-did-you-think-of-the-film* type questions, and more toward thoughtful insights about the film.
- Should there be different drugs for different races? This question was another *critical inquiry*, designed to nudge the participants to share their opinions on the overall topic.

The second topic of questions focused on racialized identity. A few examples of questions from the second topic were:

- Is it important for members of your race to have knowledge of race based medicine?
- Which social categories of race do we place Afro Arabs, or Afro Latin Americans?
- Does a race based medicine have any effect on your racialized identity – the way you self-identify racially? If so, how? If not, why not?

- After watching the film performance, what does race based medicine *feel* like?

The last question was a left-brain inquiry. Tracy, Lutgen-Sandvik and Alberts (2006) explain that questions like this can be a “catalyst for members of teams to ‘say the unsaid’ both on an emotional/psychological and on a political level” (p. 156).

The third topic of questions were ideas for future directions and recommendations, as it related to both race based medicines and future film/media endeavors. A few examples of questions in the third topic were:

- What suggestions can you make that will help the film involve the viewer, rather than talking at them?
- How can various other media contribute to raising awareness about race and race based medicines? Which media?
- If you had a chance to speak to some of the larger pharmaceutical companies, or to the agency that approved BiDil®, the U.S. Food and Drug Administration (FDA), what is the one thing you would want them to know about your thoughts on race based medicines? This was a *big picture* question. I included a big picture question here to help me uncover possible themes that had not been considered by me up to this point in my research.

At the end of the focus group interview discussion, I presented the participants with a final questionnaire. That questionnaire, Film Screening and Discussion Evaluation Form

(Appendix G) asked participants to rate the discussion in the focus group itself. A few examples of the questions were:

- [Rate how well] the discussion helped me process information about the film.
- [Rate how well] the discussion changed my opinion about the film.
- [Rate how well] the discussion changed my opinion about race based medicines.

The bottom half of the Film Screening and Discussion Evaluation Form (Appendix G) also asked participants to rate the film. A few examples from the final questions were:

- [Rate how well] watching *The Colored Pill* raised my race based drug awareness.
- [Rate the importance of] members of my race [having] knowledge of race based drugs.

After the final questionnaire, Film Screening and Discussion Evaluation Form (Appendix G) was turned in, a quick debriefing and wrap-up took place. This allowed participants a final opportunity to ask questions and share their thoughts and feelings before the session ended.

### **Method of Data Analysis**

The method I used to analyze my data was transcription from audio recordings. In this section, I describe the steps I utilized to code and interpret my transcript data. Currently, there is very little research that examines film audience knowledge of race specific medicines via film performance. Additionally, there is little evidence that

analyzes public opinion about race based medicines. What little research exists would suggest that public belief about the effectiveness of race based drugs differs by racial identification (Bevan, Lynch, Dubriwny, Harris, Achter, et al., 2003; Condit, Templeton, Bates, Bevan, & Harris, 2003; Marco, 2010). In order to better understand the knowledge of race based medicines, held by communities of color, I needed to collect current data on the topic, and then analyze the affect my film performance had on currently knowledge levels.

In this section, I introduce my process of focus group data analysis. Silverman (2011) notes that, “more information is available about how to *collect* [focus group] data than how to *analyze* them” (p. 210). Unfortunately as I searched for ways to analyze and break down my data into something intriguing but less complex components, I ended up blinking owlishly. Silvermans’ (2011) warning proved to be correct. It is for this reason, that I created a custom-designed, thematic method to analyze my focus group data.

My data collection method created two sets of data to be analyzed—questionnaires and focus group interview data. Ultimately, the multi-layered method of data collection was useful because it directly related to the investigation of my research question, relevant to the acquisition of knowledge. Of the two categories of data collected, the first came in the form of questionnaire data. The second data set was made up of discourse that emerged from questions posed after the film was screened, all of which was captured on audio recordings. My questionnaire data was taken directly from the surveys themselves; however, in readying my focus group interview transcript data for analysis, I chose to use a deductive, content-oriented method. I chose a content-



oriented method because it was important that I focus my participants only on a particular content, in this case, discourse that supported the acquisition of knowledge. Therefore, in my data analysis, I analyzed only focus group discourse that was directly relevant to, or showed, new, in-depth understanding of racialized medicine. How did I handle this? I handled this through a deductive, thematic analysis of my interview data. Before I describe that process, I first need to go over the steps I took to handle the data.

### **Data Handling**

I have the sole rights to the film and to the data. In addition, for legal considerations, decisions were made by me, regarding storing and archiving the film. Copies of the film were not made, or distributed, as a part of the focus group process.

At the end of each focus group session, I returned home with audio recordings of interviews. Immediately after each session, the audio recordings were uploaded to a password-protected file, located on my personal computer. My personal computer is accessible only by passcode. With audio recordings uploaded, in keeping with discourse analysis, I first just sat and thought about the interviews. While many researchers do not include this step as a part of their data analysis, I view the stopping-and-thinking step to be a foundational part of analysis. In this thinking through stage, I made initial connections regarding congruities between what I had just heard in the focus group, and pre-established coding themes, which will be discussed later in this chapter. In so doing, I thought deeply about whether my planned analysis strategy would fit my captured data. If there was not going to be a fit, I needed to address this issue early on.

After the thinking stage, I listened, all the way through, to the interview recordings. I knew that just in the listening process, there may have been an opportunity for initial data analysis. Because I just listened, I was able to make little notes about what I heard, creating early work toward attaching data to my codes.

Next, I began transcribing the audio tapes onto my computer, placing the transcripts in a double-spaced format. The transcribing process took place by each interview session. In other words, each interview session had its own original set of transcriptions. Transcribing by interview session, kept my data organized by focus group.

To ensure accuracy, I quality checked my transcripts against the audio files, several times. At this point, I had amassed quite a bit of rich, thoughtful feedback, opinions, and beliefs from my participants, but my data was not at all organized into a manageable form that I could code.

Despite creating a mass of recordings, I continued typing discourse from the focus group, verbatim, including verbal fillers like *ummm*, *uhhh*, or *ahhh*. Additionally, I kept a record of the actual question posed by myself, serving as the moderator. While typing, I separated lines of dialogue with line breaks. For privacy, I did not list actual names of participants. Instead, I assigned a code number for each participant.

Once the transcribing process was completed, I made two copies of each transcript, so that one transcript remained clean and intact. My rationale for this is that in the future, I may need to have one completely intact transcript, free of notes, to serve as a reference.

Having already assigned a code number to each focus group participant, I stored the key to my participants' identities and code lists in a separate, secure, and locked file. All of my transcriptions are retained and stored on my secure, password-protected computer. The signed informed consent documents are kept locked in a drawer separate from the memory device with the recorded interviews. Data will be retained for five years after data analysis was completed. After five years, all recordings and materials will be destroyed.

After transcribing the audio tapes, I once again, checked the accounts by listening to the tapes again. Both for purposes of accuracy and to have within my reach a good, generalized view of the interview data, I did a close reading of each transcript. The reading alone is a critical qualitative step, but in my study I did not stop there. I read and re-read each typed transcript in entirety, while listening to the audiotaped recording. It should be emphasized that this was not just passive reading. Instead, I actively sought those thoughts and interactions, from the transcripts, that supported my codes. In fact, I was able to do a bit of *pre-coding* while I transcribed my focus group interviews. Capturing a sentence or phrase uttered by a participant, during transcription, I would highlight those comments that I believed would support my previously selected codes.

Having now explained the process I used to handle my collected data, I will now explain the custom-designed, thematic process I utilized to analyze my data.

### **Thematic Frame**

For purposes of analysis, my transcript data was organized, by participant response, into thematic elements aka thematic codes. The purpose of my utilizing

thematic codes was to measure participant dialogue against increases in knowledge. In fact, each code was used to measure the extent to which my participants' comments proved the film was a tool that elevated their knowledge. Saldaña (2011) explained thematic analysis of interview data as the process of analyzing transcript interviews into topics or ideas relevant to the research study. McCracken (1988) spoke on the process as utilizing themes from interview data that directly compare to the research question. Finally, both Erickson (1986) and Silverman (2011) discuss the importance of utilizing themes to analyze interview data. I chose to analyze my data via thematic themes because this method best pointed to the nature of knowledge (epistemology) and specifically, the advancement of knowledge, which is an aim of my research question. For this reason, my study coding consisted of *only* identifying the parts of my data (transcript interviews) that best exemplified my key concepts, which I also refer to as my thematic codes.

Early on in my research design, I realized my viewing audience needed to be persuaded that although my film is a fictional account, it was based on true events. Naturally, I hoped my film would be liked, but the greater goal of my film was to intensify knowledge. Thus, my data analysis needed a frame whereby the objective meaning (knowledge production) of the film could be measured.

I found inspiration for an effective thematic frame from former Yale social and political psychologist, William James McGuire (1968, 1969, 1972, 1978, 1983, 1985, 1986). McGuire's creative, sequential, information-processing model modestly shaped interdisciplinary studies in communication, political science, and sociology. Jost and Hardin (2011) illuminate, "As a left-handed, self-identified ethnic Catholic from a

working class background, McGuire often perceived himself as a minority figure in the academy” (p. 39). I found peculiar similarities between McGuire and myself, as we were both raised as ethnic Catholics from working class backgrounds. In McGuire’s description of his deviation from the academy, I could also see similarities between him, myself, and other scholars I looked up to as part of this study, namely Dr. Dwight Conquergood and Dr. D. Soyini Madison. I was hooked. I needed to know more about McGuire, his information processing model, and how his model might assist me with my data analysis processing.

I learned that McGuire (1968, 1985) used communication in his description of what he called the *communication/persuasion matrix*—a matrix of change variables in the communication process. Initially, McGuire’s (1968) communication/persuasion matrix only included three stages—attention, reception, and yielding. Later, McGuire’s (1985) approach expanded, incorporating several other elements to the mix. McGuire finally settled his information-processing model with six hierarchically ordered stages. I found McGuire’s’ model so relevant to my study that his first four stages, became my four key thematic codes. His information processing concepts closely reflect my own thoughts on how we come to know, what we know. His model also matched my thinking on how individuals utilize information processing to increase knowledge. In this regard, my positionality was a strong element in guiding me toward McGuire’s (1985) approach to information processing, as the foundation for my coding technique. Agreeing with McGuire (1985), I adopted his information processing stages, knowing it would help

me make simple, yet compelling codes, which would efficiently fit with my focus group transcript data.

Prior to conducting focus group interviews, I allowed four of McGuire's (1985) information processing stages to serve as my four codes. Charmaz (2014) refers to codes as the "bones" that form the "skeleton" of grounded-theory analysis (p. 45). In this respect, if codes are the *bones*, then I see McGuire's (1985) approach as the *meat* on those bones because it provided a step-by-step process for the way we acquire information.

In my custom-designed analysis, my four codes/themes were not only directly relevant to information processing; they were directly relevant to depth of knowledge concepts, drawn from my research question.

All four of my codes/themes are important stages in the acquisition of knowledge. The four themes, presented in Figure 9 below, were: *exposure*, *attention*, *comprehension*, and *acceptance aka yielding*.



Figure 9. Themes

As I stated before, McGuire created six information processing stages. His final two stages—retention and behavior—were not used in this study. Due to the nature of this work, I believe those two stages are best suited for follow up studies.

### **Data Management**

My process of data analysis began shortly after transcription, in what I think of as the data management stage. In my view, this process began with a general reading of all of my collected voices from transcription. Lindlof and Taylor (2011) share the goal of data management is in, “gaining control over data that tend to grow rapidly in a project” (p. 243). In order for me to gain control over my data in this first part of my data analysis, I read and re-read the interview transcripts. By reading over my transcripts several times, I was able to look at my data in ways that helped me explore the depth of the discourse shared. Specifically, I could see how that discourse fit into my established themes—*exposure, attention, comprehension, and acceptance aka yielding*.

For example, one of my focus group participants shared, “*This is the first I’ve heard about race based medicines.*” The structure of that sentence shows a revelation about being exposed to information displayed in the film. With that, I knew this participants’ comment would fit nicely into the *exposure* theme. Another participant made this comment, “*I felt like I was right there, back when this stuff was happening!*” From that comment, I knew that statement would fit into my *attention* theme. Yet another viewer expressed some frustration, when he had this to say, “*If there was a way I could go back in time and put a stop to all this race based crap I just learned about, I would!*” Again, I knew his statement would fit into my comprehension theme. Finally, one

participant shared, “*It’s hard, but I know this kind of stuff is true.*” That comment fit into the *acceptance* theme.

By joining together some of the more significant views from my participants, to my four established themes, I could easily gain control over my transcript data that had mushroomed to hundreds of pages. By considering and prioritizing the feelings, rich narratives, and opinions of my participants into themes, I was not only able to better manage my colossal data, I was also better able to prepare for one of my final stages of data analysis, that is, data reduction.

### **Data Reduction**

As they did with data management, Lindlof and Taylor (2011) did an excellent job explaining the process of data reduction by noting “this does not mean that data should be thrown away like chaff; you never know when chaff, or unused data, might become wheat in another work context” (p.243). In keeping with the views of Lindlof and Taylor (2011), I did not look at the data reduction stage of the process as simply tossing away data. Instead, I looked to extract only the data that would be most useful to my analysis. My aim in data reduction was to give shape to the thoughts and views of my participants. Since I came to data analysis with four core themes in mind, I looked for focus group views, narratives, and opinions that specifically supported those themes.

### **Deductive Coding Analysis**

In this section, I provide an overview of my general, deductive coding approach. In a subsequent section, I described, in detail, my process for manually coding my data using a thematic frame. Under that thematic frame, I decided on a deductive approach. I



decided on a deductive approach because I knew I would approach my data with pre-determined themes. Roberts, Dowell and Jing-Bao (2019) share, “Deductive approaches are based on the assumption that there are ‘laws’ or principles that can be applied to the phenomenon” (p. 2). To be clear, my aim, through the adoption of deductive coding, was to identify instances of knowledge elevation from focus group interviews. The use of McGuire’s model of information processing fit well with my deductive coding approach because it allowed for the use of a template of pre-established codes/themes from which I could interpret my data. As a means of organizing my data, I defined McGuire’s themes prior to beginning the analysis of my transcript data. In this respect, my pre-established themes that would indicate knowledge elevation were: *exposure*, *attention*, *comprehension*, and *acceptance aka yielding*. These themes were assigned a priori, based on the goals and theoretical framework of this study.

To provide the best perspective for this study, I needed to focus on my units of analysis. My units of analysis are all the statements and comments, taken from my transcript data, which constitute examples of knowledge advancement. I relied on my codes to help me capture all of the relevant excerpts from my transcript data. My pre-established codes played an important part in helping me mark all of the places in my transcripts that contained my units of analysis.

Charmaz (2014) articulates, “Coding is the pivotal link between collecting data and developing an emergent theory to explain these data” (p. 46). It was fortuitous that I discovered McGuire’s (1985) information processing stages, because not only did his stages shape my coding elements, but my coding decisions were actually made before I

reviewed my transcript data. McGuire's (1985) information process method made the process of utilizing pre-defined themes, surprisingly simple. Auerbach and Silverstein (2003) posit that themes function to categorize data into "an implicit topic that organizes a group of repeating ideas" (p. 38). Owens (1985) opines that themes are the *building blocks* for qualitative research. I could not agree more with both scholars.

Using themes taken from McGuire's (1985) information process model, I coded my data deductively by looking for information that fell into one of the pre-established themes. The first theme from McGuire's (1985) information processing model was *exposure*. Early on, I knew the actual screening of the film would very likely sufficiently satisfy the theme of exposure. I anticipated that most of my participants would not have heard much about racially targeted medicine. With that, I was not concerned about finding potential participants who would reiterate, in focus groups, how the film *exposed* them to new knowledge and information.

My second coded theme from McGuire's (1985) information processing model was *attention*. I knew that in creating a compelling and dramatic film performance, my participants would feel that I had satisfied this stage. In fact, so sure was I about the attention-getting nature of the film, that one of my Post-Awareness questions asks whether the focus group considered the film to be *compelling* and *dramatic*.

My third coded theme from McGuire's (1985) information processing model was *comprehension*. I knew I could satisfy this stage by asking my focus group a comprehension-type question in the Post-Awareness Survey (Appendix F). I had such a question in that Survey. That question asked my viewers to answer, in their own words,

what is race based medicine. If my focus group members could adequately answer that particular question in a Post-Awareness Survey, when they could not answer it in a Pre-Awareness Survey, I would have my proof that *comprehension* had taken place. The evidence of comprehension was also revealed throughout the post-screening focus group discourse.

My fourth coded theme from McGuire's (1985) information processing model was *acceptance*. This theme was my most critical code. After all, an advancement of knowledge would not take place, if the films' message were not accepted. For this fourth code, I was convinced the focus group discourse held immediately following the film screening, would uncover the impact of the film on the audience, and their acceptance of the film message. So great was my focus on this final code, that nearly the entire decision to utilize this customized coding method, for my discourse analysis, rested upon it.

Given that this study takes a decided qualitative approach to the advancement of knowledge, each of the above mentioned areas served as excellent codes for data analysis. What greatly helped me organize and analyze all of my discourse data (interview transcripts) was the use of a deductive approach to coding the data.

Using a deductive coding analysis technique was particularly insightful in identifying and understanding how the transcript discourse connected to my pre-established themes. Providing a clear trail of evidence, McGuire's (1985) model for information processing allowed for a deductive way for me to apply the pre-established codes to my transcript data with the goal of identifying supporting data from that data. With a focus on actual words and phrases being a tenet of information processing, I knew

to listen and re-listen to my audio recordings from the focus group interviews. Through deductive coding analysis, I knew to search for re-occurring and/or repetitive words and phrases that would indicate knowledge elevation. By doing so, I was not only embedded in the reflections of the data, I was also able to capture salient quotes from participants that supported my four themes—exposure, attention, comprehension, and acceptance.

Next, I faced several hundred pages of interview transcripts that needed synthesizing. I selected deductive coding because it allowed me to utilize pre-defined codes associated with information processing, which by the way, aligned with the framing of my research inquiry. Having selected a deductive coding approach, Gee et al. (1992) believe that some discourse analysis research should not utilize coding at all, but instead should rely on details about the transcription. Gee et al. (1992) do not support the utilization of coding in research methodologies such as performance, ethnography and narrative inquiry (Hendry, 2007; Lawrence-Lightfoot & Davis, 1997).

With Gee's (1992) conflicting opinion swirling in my head, at one point, I considered not utilizing coding at all, wondering if it were possible to have my research question answered through granular descriptions, from my focus groups, about the film. In the end, I decided against using just descriptive labels, as I believe that would have only created a descriptive response to my question, as opposed to discourse that was more *prescriptive* in nature. Again, my research question asks: How does a film performance function to affect knowledge of race based medicines, as opposed to just *does it* function to affect knowledge. In my view, the *how does* nature of my research question is much more epistemological in nature, which goes beyond just having

participants provide a catalogue of observable descriptions from the film. Instead my research question calls for an exploration of the underlying *prescriptive* process—*how does* knowledge happens. Here, I once again, call on McGuire's (1985) deductive method, as I believe his stages of information process point to the process of *how* knowledge takes place.

Having previously decided on my four codes, deductive coding was the most fitting process for me to utilize because it provides a substantive analysis of data, at the message level, based on pre-defined themes. This is something I was looking for in my study. After all, the focus group discourse is the unit of analysis for this study. Given that, I knew that message-level, deductive coding was going to be instrumental for me to use.

While on the topic of coding, I should reveal that I coded alone. Despite that, it should be noted that I had another researcher (working on a different topic) that I would, from time to time, discuss my coding and analysis with. Those discussions were invaluable, not because my colleague could help me with my coding (they could not), but because talking through my coding decisions helped me solidify the decisions I made regarding analyzing my data.

### **Applied Coding**

Drawing on grounded-theory practices, during the applied coding phase, I allowed my data to flow into my themes/codes, instead of fitting the focus of my research into a specific theory. While both parts of my inquiry—questionnaires and focus group interview data—have traditional and longstanding ties to each other in qualitative

research, I chose to analyze the closed-end questions posed in my questionnaire and the open-ended questions posed in my focus group interviews, independently.

The tool I utilized for my applied, manual coding was a very familiar one for me—Microsoft Word. The way I accomplished this was I first created a typed transcript, of each audio recording, in Microsoft Word. It cannot be emphasized enough how slow and arduous the process of transcription was; however, the good news is the investment of creating detailed transcription paid off. In the end, I had a complete and verbatim account of every focus group interview. With that in hand, I was ready to overlay my pre-established themes onto the transcript data.

Again, I identified four pre-established themes, directly related to my research question of knowledge production.

Themes:

1. Exposure
2. Attention
3. Comprehension
4. Acceptance aka Yielding

With my themes firmly in hand, I combed through my transcript data, searching for focus group discourse that supported each theme. Recalling that my units of analysis are all the phrases and sentences from the discourse that indicate knowledge advancement, I read through the discourse in my transcript data, repeatedly asking myself, is this sentence an example of a response that supports the exposure theme? Or, is this phrase an example of a response that supports the attention theme, and so forth? To

make this process simple, each of my themes served as an example of an increase in knowledge. Now, my job was to find only those statements or phrases that supported my themes.

### Theme 1. Exposure

The first theme to be coded, from McGuire's (1985) information processing method, was *exposure*. It was my belief that many individuals are unfamiliar with the topic of race based medicine, which gave rise to the question of exposure. In order to acquire a depth of knowledge, an individual must be exposed to information. This is true for any type of transfer of knowledge. With knowledge as the backdrop, I believed it fitting to utilize exposure as a theme for this study.

Searching for focus group transcript discourse that provided evidence of *exposure*, one participant exemplified the theme when she expressed, "*Wow, I guess, uncovering this part of history is good and bad. The problem is, now that I know, I have to figure out what to do about it.*"

What is notable about this response is not only is it an example that supports the exposure theme, it also points to the emotional duality of the theme. In the above example, the participant spoke of being exposed to an element of history, as something she is grateful for. At the same time, the participant's comment illustrates how she felt torn by knowing. In fact, the participant felt so torn, that she now must make a decision about how to handle the increased knowledge.

Another participant illustrated exposure when she spoke on family memories:

*I first learned about race drugs from my parents, and they learned about it from their parents and even their grandparents. They were from the South and they didn't call it 'race drugs', but they always told me about what happened, with, you know, Blacks back then, and they always said it could happen today. So, I guess with that one FDA drug, it really did happen again.*

In a similar fashion, another participant spoke of the wisdom of the elders in their family, as it relates to this topic. The participant shared:

*My mother said that our grandfather had some experiments done on him, on account of being mixed race. I guess he told her about it when she was little. He said that some of the things they did to him made him go crazy, and that's what was wrong with him when she was little. She said that's why he drank. Now I can see it for myself in what happened to some of the people that had race drugs forced on them.*

Building on existing knowledge was evident in the above two participant comments. In the above two comments, while participants had been previously exposed to this information, or related information, being re-exposed expands the theme.

Another participant illustrated the exposure theme when she announced, “*Mind blown! I had no idea this was happening!*” This participant hit on exposure when she simply shared, “*Thank you for showing me this film. At least now I know.*”

One participant had this to say, “*I had no idea. I seriously could do more research on some of this.*” That kind of sentiment was shared several times, with other participants



making comments like, “*Where have I been? I never heard about this*”. Or questions like “*Why have I not heard about race based drugs before*” to “*Man, somebody should of told me they put race in the medicine!*”

The emotional element related to exposure was clearly visible from the above participant comments. All of these comments, taken directly from my transcript data, were coded into my *exposure* theme.

## Theme 2. Attention

The theme of *attention* served as my second code. Here, I searched for words and phrases, from my transcript data that indicates the films’ message had captured their attention. Indeed, participants shared several examples of this code when using phrases like, *new awareness* and *now in my consciousness*. One participant contended that, “*Race based medicine is a terrifying concept that I was not aware of before today.*” Another simply stated, “*The film was really interesting and I enjoyed watching it.*” While those statements were succinct, they did a great job in supporting the attention theme. A few participants made similar comments to each other, saying, “*This film definitely makes me want to look into BiDil now and find out what else is happening with race based medicine.*” Another stated, “*BiDil is definitely on my radar now.*” Still another viewer revealed, “*Okay, I admit, I never heard of BiDil before, but now my eyes are open. I mean, REALLY open, and I’m going to do some digging to find out a little bit more, too.*”

A few participants discussed the theme of exposure when they shared, “*I want to know more about it now*” and “*I’m definitely telling my friends about this movie because I bet they don’t know anything about all these things in history either.*”

What is notable about these comments, related to exposure, is the way many participants felt spurred to action after viewing the film. Each comment, extracted from the transcript data, was coded in my *attention* theme.

### Theme 3. Comprehension

The third theme to be coded was *comprehension*—an assessment of the extent to which my participants understood the films’ message. It seemed to me that independently, themes of *exposure* and even *attention* may not be enough to advance knowledge about race based medicine. All that changed with the theme of comprehension. In comprehension, I looked for focus groups participants to use words and phrases that showed they truly grasped the concept of racialized medicine.

An example of a response that supports the comprehension theme came from this participant:

*It’s hard for me to even comprehend that this is an actual thing and that people are okay with it. But, I guess I shouldn’t be surprised because it’s been happening for years, and will probably keep on happening until we do something.*

Another participant pinpointed comprehension, when she revealed:

*I can’t believe that this is even real, but I understand why it keeps happening, and I understand about why they’re making those drugs. It’s just racism. [Pause] It seems to me that we haven’t changed much from the past.*

What was interesting about the comments above, related to comprehension, is the way participants indicate their wrestling with disbelief. One participant spoke of being surprised, while the other said she could not believe it was real. As a filmmaker, it is

important that viewers suspend their disbelief. That feeling was even greater in this film, since my aim was to increase knowledge about real-world events.

Another participant shared this:

*One of my friends was just talking about how his great, great, grandparents were experimented on, I think it was back in the 40s, and how they did it because they're Black. So, it was so weird to see some of this in a film.*

Of great interest to me in the above comment, was the way the participant related elements of the film atop information relayed by a friends' grandparents. For me, the comments from the grandparents greatly supported information in my film, and I was thrilled to hear it. Comments like this, uttered by multiple participants, were of great value to me, particularly when participants compared the film to details they had previously heard related to the Tuskegee Syphilis Experiment. It was interesting to note, how many participants nodded their heads in agreement in the discussion about the Tuskegee Experiment, when earlier, most of the participants indicated they had no prior knowledge. Nonetheless, participants became somewhat emotional when reflecting on and connecting the Tuskegee Experiment to the events in *The Colored Pill*.

On the same topic, another participant had this to say, "*Actually seeing this race stuff, like Tuskegee, on film just makes me that much more determined to spread the information to as many people as I can.*" Finally, one participant spoke about their comprehension of the films' message when she stated:

*The potential implications of using race in medicine is so far reaching and uh, scary that I hope it does not go any further because if it does it could go back to*

*like in Tuskegee, we could end up with race based insurance, segregated hospitals, segregated medical schools, and who knows what else?!*

Each comment, extracted from the transcript data, was easily coded into my *comprehension* theme.

#### Theme 4. Acceptance

A fourth and final theme was *acceptance*. Of significance to this particular theme is the fact that film, as a source of knowledge, is dependent on acceptance of its message. Coding this section, I searched for parts of the discourse that indicated the participants viewed the film information as true and plausible. I specifically looked for pathways showing a flow from comprehension to acceptance.

Participants indicated acceptance when they spoke about receiving information, in fact many participants spoke to this. Some participants made connections between the code of acceptance and depictions in the film, when they used words like *learned* and *educated* to describe their feelings. One participant provided an example of a response that supports the acceptance theme when she shared that she, “*was now educated in race based medicines.*” Another, said that he had “*learned more than I thought I would,*” to describe his views.

In support of the theme, one participant stated:

*I have a bad feeling about these kinds of drugs and I think they're gonna' cause a lot of trouble. Personally, I think pharmaceuticals are a money ploy in the first place. So to me, watching this film, I guess I see humans being treated like caged animals so the pharmaceutical industry can make a buck.*

Other participants expressed outrage, as they shared their acceptance of the films' message. One participant said it this way, "*THIS IS NOT RIGHT! We need to get control of our health care system again!*" Still another viewer had this lengthy reply:

*Don't get me wrong. I'm really glad that somebody took the time to put this in a movie. That's really good, so now we can't say we don't know about it, but still, I kind of hate to say this but, I don't know, it just seems ridiculous to even have such a thing as race based medicine, you know what I mean? I mean, what's the point? If I get sick, it's 'cause I'm Hispanic? Come on, how does that make sense? I'm not talking about the movie, no, I'm not talking about the movie at all 'cause at least the movie taught me something. I'm talking about how my race doesn't have anything to do with if I get sick, but yeah, like they were saying, at least now I know.*

What was notable about these highly emotional comments is that they really drove home the concept of acceptance. Participants would not have been so emotional, if they had not fully accepted the information in the film. Statements, such as these, went a long way to support that the theme of *acceptance* was achieved. These comments, taken from the transcript data, were easily coded into my *acceptance* theme.

My process, to attach my codes to the transcript, was fairly simple. Initially, I printed out a few pages of discourse. Remembering that my units of analysis are the phrases and sentences from the discourse that indicate elevated knowledge, I specifically ferreted out only those parts of the transcript discourse. When they were found, I identified that part of the discourse by attaching a yellow sticky note that had a hand-

written code. I placed the sticky note, with the hand-written code, on the part of the dialogue that supported that code. As an example, I placed a sticky note labeled *exposure*, onto the parts of the transcript where the participants' comments prove they had been exposed to the films' message. I followed this same process with my *attention* code, and all of the other codes. I repeated this rather rudimentary process of placing sticky notes on phrases and sentences that indicate knowledge advancement over and over, until I was certain that my coding process worked efficiently. After I was sure that all was well, I switched from sticky notes and printed pages of transcript discourse, to conducting the entire process on the computer.

Switching to my computer for coding, my process worked in much the same way. Again, I read through my transcript data, in search of comments that supported my codes, only on the computer, I utilized a two-column system. The two-column system was one where I placed my interview discourse in the first, wider column on the left. Then, I placed my codes in the column on the right. On the left side was my discourse. On the right side were the codes that supported the discourse. By placing my codes directly onto the transcript, in this two-column fashion, my eyes could easily glide down the page and identify which codes went with the corresponding discourse.

To make my codes even easier to see at a glance, I selected a specific font color for each code. For example, for the exposure code, I chose a blue font. For the attention code, I selected a red font. I utilized this color-coded process for each of my four codes. Again, when glancing at my transcript data, I could easily spot instances of my exposure code, just by seeing the colored font on the page.

In addition to color coding the codes, I also highlighted/shaded key words and phrases within the transcript. The purpose of the highlight was to make the phrases and sentences, from the discourse where knowledge advancement was indicated, stand out from the rest of the dialogue. For example, in one excerpt from the transcript, one participant made the comment, “*I came here knowing nothing about race based drugs, but now I at least know there is such a thing.*” I decided to code that participant comment as *exposure*, as that sentence served as an example of my unit of analysis. Deciding on the *exposure* code, I typed the word exposure in a blue font in the right hand column. On the left side of the page—the discourse side—I highlighted the entire sentence in blue. Following this method, I could glance down at each transcript page, quickly spot my code, and just as quickly see the sentences or phrases that supported that code.

Using this color-coded process for all of my transcripts allowed me to organize vast amounts of data from what was once clunky and difficult, to something that was easy to recognize, and also easy to manage.

### **Reliability and Validity**

Due to limitations in funding, I did not have the opportunity to employ others to help me transcribe my data. I was just not able to employ multiple coders. Olson et al. (2016) opine that while the use of multiple coders can increase validity, they argue that multiple coders have the potential to reduce reliability because of possible coding inconsistencies from analyst to analyst. While my reading and re-reading process may have seemed excessive, I knew that as the sole coder, I needed to work even harder in

order to be sure that my transcript data was as accurate, and free from errors, as humanly possible.

To ensure reliability, I made a practice of closely inspecting my data—listening and re-listening to my taped interviews as well as reviewing and re-reviewing each transcript for mistakes. Additionally, after coding a few sections of data, I would go back and compare my own coded data with other coded data. I did this several times to insure that similar comments were coded similarly.

As the sole coder, I did not have reliability concerns that those with multiple coders might have, such as coders not being familiar with the data. As the sole coder, I was not hindered by differences, between coders, in adherence to established themes. I also did not have to reconcile concerns with varied coders about differences in data interpretations, however, complete accuracy and total reliability were areas that were difficult to accomplish by myself. However, in order to add to the credibility of my study, I looked for conditions of validity, namely those times when I might assess the rigor of reliability in my transcript analysis. This was no simple feat since my data was based on focus group interviews, and therefore, not replicable. Knowing, however, that reliability is an important feature of good research, to counter this limitation, I collected as much data as possible until I reached what I deemed as multiple layers of concrete information.

Not only was I concerned about reliability in this study, in order to improve the integrity of my research, I embraced those opportunities where I could address the various ways of knowing related to validity. Because the themes I utilized were custom-



designed to measure the elevation of knowledge, being able to evaluate the validity of this measure was somewhat restricted.

One way I addressed reliability in this study was to include real-world examples of thoughts and opinions spoken in the focus group, throughout my analysis. My thinking in doing so was that providing examples from the focus group makes my data much more transparent, dependent, generalizable, and easier to interpret. Analyzing the data in this real-world thoughtful manner, also allowed me to discern whether or not, my participants understood the information presented in the film. With the clear foci for this study being the elevation of knowledge, the transcript data served as evidence to be analyzed that would uncover that advancement of knowledge.

My focus on validity actually started early on, with the creation and development of my questionnaires. For purposes of validity, I carefully worded those questions where the meanings were crystal clear. I certainly did not want to make mistakes in this area. To get different views, I tested these questionnaire questions on colleagues, friends, and family to ensure that my wording was easily understood.

My focus on validity also extended to my transcript analysis. One of the early decisions I made related to validity, was the selection of a reliable, straightforward coding protocol. McGuire's (1985) information processing technique helped me create guidelines for the discrete themes of my custom-designed coding protocol. These clearly-stated themes made for a refined coding frame, making it easy for me to navigate through a vat of transcript data with good, reliable measures. It also helped me to reliably analyze

the transcripts, which in turn, increased the likelihood of comprehensive interpretation. It also increased the likelihood of validity.

In another nod toward validity throughout this study, I made sure that my procedures would be transparent to other researchers. I have also clearly communicated my themes/codes for other researchers to follow. Additionally, my focus on validity was on display during the focus group interviews. There, I ensured that participant voices were heard, without interruption from me, or other participants in the group.

I addressed validity in my focus group transcripts by transcribing the words of each participant verbatim, making note of fillers and pauses. In fact, there were those times when participants would repeat their words, often at the start of sentences. For the sake of validity, when that happened, I transcribed participant words precisely as uttered.

Measures for this study were based on pre-defined themes that emerged from the use of McGuire's (1985) model of information processing. It is my belief that this supported the validity of the measure for this study, as well. As a validity check, I returned to each focus group transcript, at least twice, to ensure accuracy. This is in keeping with Cresswell (2013) and his discussions about performing accuracy checks that match transcriptions to recordings.

### **Results of Focus Group Questionnaires**

The first of the two results being discussed here is an analysis of the questionnaire data. The second area to be discussed is the results of the focus group interviews. Prior to screening the film, focus groups were asked to complete two, closed-ended

questionnaires. It should be noted the completion rate for all administered questionnaires was 100%.

The first questionnaire administered was a Demographic Survey (Appendix C).

The primary questions posed in the Demographic Survey were:

1. How do you self-identify: Male / Female
2. What is your ethnicity?
3. How do you self-identify racially?
4. What is your age group? 18-25, 25-35, 36-45, 46-66, 67-87, Above 88.  
Circle one.
5. What types of film do you generally like to watch? You may circle more than one. Action, Adventure, Comedy, Drama, Documentary, Non-Fiction, Horror, Musical, Sci-Fi, Romance, Indie, Other.
6. How many independent films have you watched in the past year? 0, 1, 2-3, 4-6, 7-10, More than 10.

Results from the Demographic Survey are presented in Table 1 below.

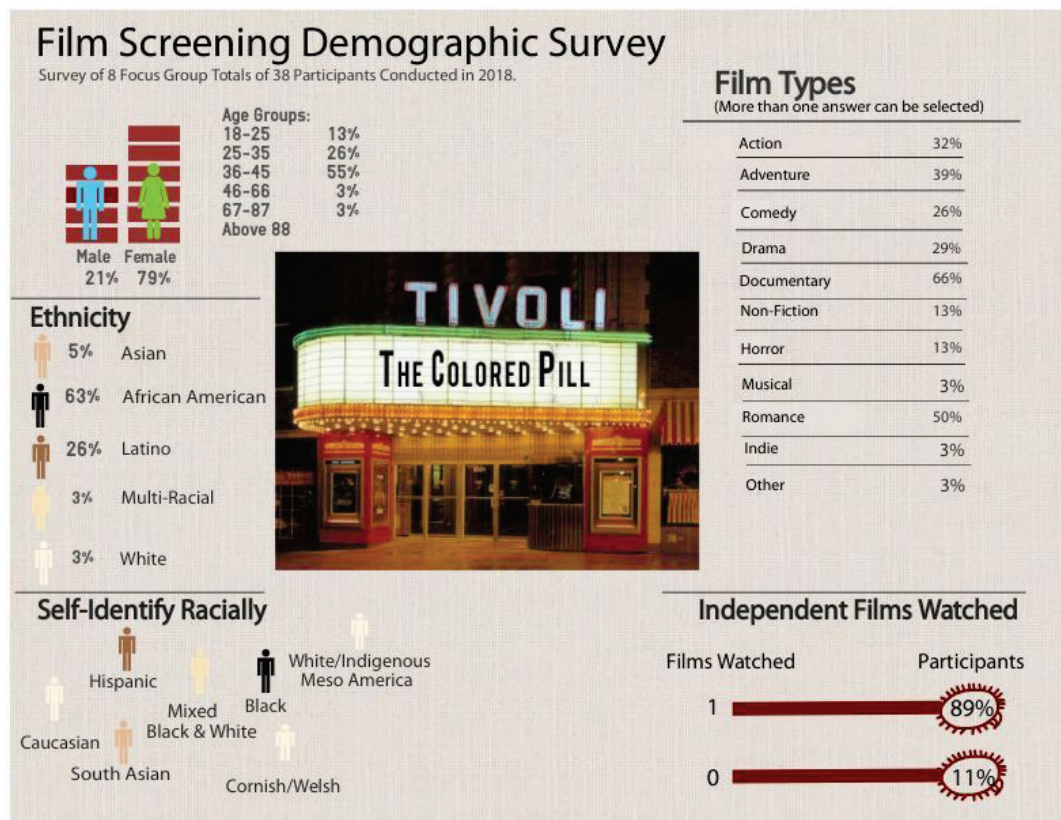


Table 1. Results, Demographic Survey

An analysis of Table 1 uncovered the make-up of focus group participants. Results reveal there were 30 females, making up the majority (79%) of all participants. Eight males in the study made up 21% of all participants.

For purposes of creating a focus group profile, a Demographic Survey, covering gender, race, age, and education, was collected. Due to the film topic, African American participants were oversampled. Results of the Demographic Survey reveal that 95% of participants self-identify as a person of color, 3% self-identify as Multi-Racial, and 3% self-identify as White. An analysis of the racial/ethnic breakdown, from the Demographic Survey, reveal that of the focus group participants, 63% were African American, 26% Hispanic/Latino, 5% Asian, 3% Multi-Racial, and 3% were White/Caucasian.

The age of participants ranged from 18 to 69. Results from an analysis reveal the average participant age was 37. While this information was not particularly surprising (younger individuals tend to view more films than older individuals), the average age here opens the door for another possible study. That future study might determine whether age difference is a factor in the practice of elevating knowledge.

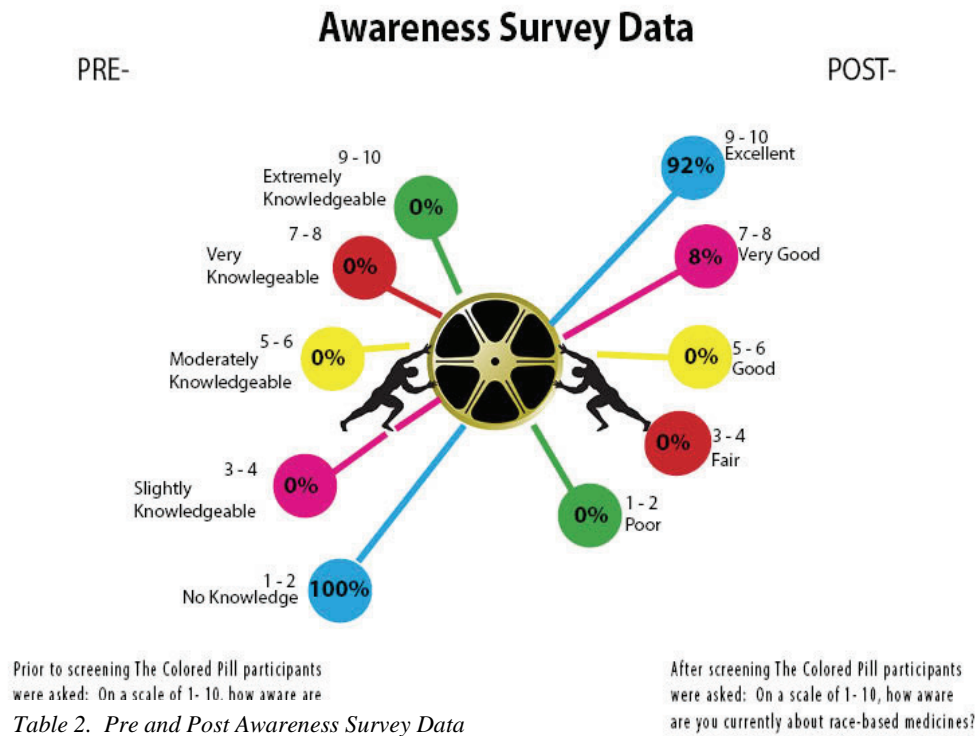
Results show that 66% of the participants held high school diplomas or GEDs, 16% of participants indicate some college/university, 13% of participants report earning an Associate Degree, 3% of participants indicate earning a Bachelor's Degree, while 3% indicated earning a Graduate Degree.

An analysis of the top five genres of films participants generally like to watch revealed: 39% chose Adventure, 32% chose Action, 29% selected Drama, 26% picked Comedy, and 13% selected Horror.

In answer to how many independent films were watched in the past year, 34 participants (89%) reported watching one film, and four participants watched zero.

The second questionnaire, administered prior to film screening, was a closed-ended, Pre-Awareness Survey (Appendix D). The Pre-Awareness Survey had quantitative results which will be discussed later in this chapter. One key question on that Survey was, *On a scale of 1-10, how aware are you currently about race based medicines?* The answer to that question was a 10-point Likert-type scale, which ranged from 1 = *not aware of race based medicines at all (never heard of it)* to 10 = *a lot of knowledge about race based medicines (i.e., read articles, seen it discussed in other media, have held numerous conversations about it, etc.)*. Results show that 100% of the participants

selected numbers one or two (i.e., not aware of race based medicines at all) as an answer to this question.



Results of this question reveal that an overwhelming majority—97% of participants—specifically selected number one as their answer, meaning they had never heard of race based medicines. None of the participants selected answers higher than number two. An analysis of that Survey question helped me uncover evidence on race based medicine awareness levels *prior* to film screening.

After the film screening, two additional questionnaires were administered. The first was a Post-Awareness Survey (Appendix F). The Post-Awareness Survey had quantitative results which will be discussed later in this chapter. Responses to the Post-

Awareness survey helped shape this study in that those responses, along with focus group interview discourse, determined if *The Colored Pill* was successful in affecting knowledge.

One of the first questions on the Post-Awareness Survey was a 10-point Likert-type scale question (1 =*poor* to 10 =*excellent*), which asked the participant to indicate an overall evaluation of the film. Results uncover that knowledge about race based medicines improved significantly following the film screening. A key question, posed on the Post-Awareness questionnaire, asked: *Please provide a short answer to the following question. Your answer will help us understand how much the film raised your awareness. In your own words, what is race based medicine?*

Results from this question proved that, as a result of watching *The Colored Pill*, the majority of participants could define racialized medicine. Some of their written comments ranged from:

*Race based medicine specifically targets a racial population.*

*Race based medicine is medicine that targets people of a specific race/ethnicity.*

*Race based medicine is a drug that was made specifically for people of color. It is a drug that will cause many problems in the future.*

*Race based medicine is any medicine geared or said to be only for specific races/ethnicities.*

*It is medicine which is prescribed specifically to a certain race, though the race doesn't really make a difference for the health issue.*

*This is a medicine for a certain race, however, they never checked if it worked on other races.*

*It seems to be a drug or combination of drugs that could be used on only a single race.*

*Race based medicine is where drugs and/or medical experiments are conducted to target a single race of people. Yes, while there may be diseases and illnesses more common in between different races (such as sickle cell) a drug should not scientifically be able to work on a single race because race is a social classification.*

A few participants spoke specifically about the drug, BiDil®:

*BiDil is a medicine that was only tested on a singular ethnic group.*

*I think the drug was created for profit and to serve as a diversion/division of people.*

*The drug, BiDil, may have been created for heart failure, but what it does is it fundamentally divides people.*

*BiDil is eugenics all over again. Race based medical experiments, just like Tuskegee.*

Some participants were much more philosophical when answering this question:

*Race based medicines are meant to heal people of their race, but it's based on unscientific evidence. Science isn't exact anyway.*

*Race medicines are normal medicines that are labeled race based.*



*I think it can be said it is a medicine that is effective, but at the same time, it is not effective because it targets a specific race.*

One participant went even further with their views, stating:

*Raced based medicine seems to be a fallacy used to make a distinction between members of the same species. Humans are genetically and essentially the same, so it seems ridiculous to base a human drug on a social construct.*

Another key question, posed on the Post-Awareness Survey, consisted of a 10-point Likert-type scale (1=*poor* to 10=*excellent*). The question posed was, *On a scale of 1-10, how aware are you currently about race based medicines?* Results show that an overwhelming majority of the participants selected nine or ten (excellent or close to excellent) for this question. Results reveal that 92% of the participants selected nine or ten as answers to this question.

The comparative results, between the Pre- and Post-Awareness Surveys, presented in Table 2, could not be more interesting. Prior to film screening, results showed that 100% of participants were *not aware of race based drugs*. Results show that after screening *The Colored Pill*, a majority of participants (92%) indicate they have *excellent knowledge*. These results show the film moved the continuum of the advancement of knowledge quite severely—from *not aware*, to having *excellent knowledge*. To test the research question of how a history film performance functions to affect knowledge of race-based medicines, a one-tailed, paired-samples t-test was run. The t-test was significant ( $t[37] = -83.98, p < .001, \eta^2 = .99$ ). Participants' average level of knowledge of race-based medicines was greater after viewing the film ( $M = 8.89, SD =$

.51) than it was before viewing the film ( $M = 1.03$ ,  $SD = .16$ ). Reflecting on my research question, I was excited by these astounding quantitative results.

The final questionnaire administered post screening was, THE COLORED PILL: Film Screening and Discussion Evaluation Form (Appendix G). This questionnaire concluded the study. Results from this questionnaire are presented in Table 3 below.

In the Film Screening and Discussion Evaluation Form, participants were asked to indicate their responses on a 4-point Likert-type scale (1 = *strongly disagree*, 2 = *disagree*, 3 = *agree*, and 4 = *strongly agree*). The first half of the questions on this questionnaire was specifically about the discussion. Those questions were:

1. The discussion effectively met my expectations.
2. The discussion helped me process information about the film.
3. The discussion changed my opinion about the film.
4. The discussion changed my opinion about race based medicines.

## Film Screening and Discussion Evaluation

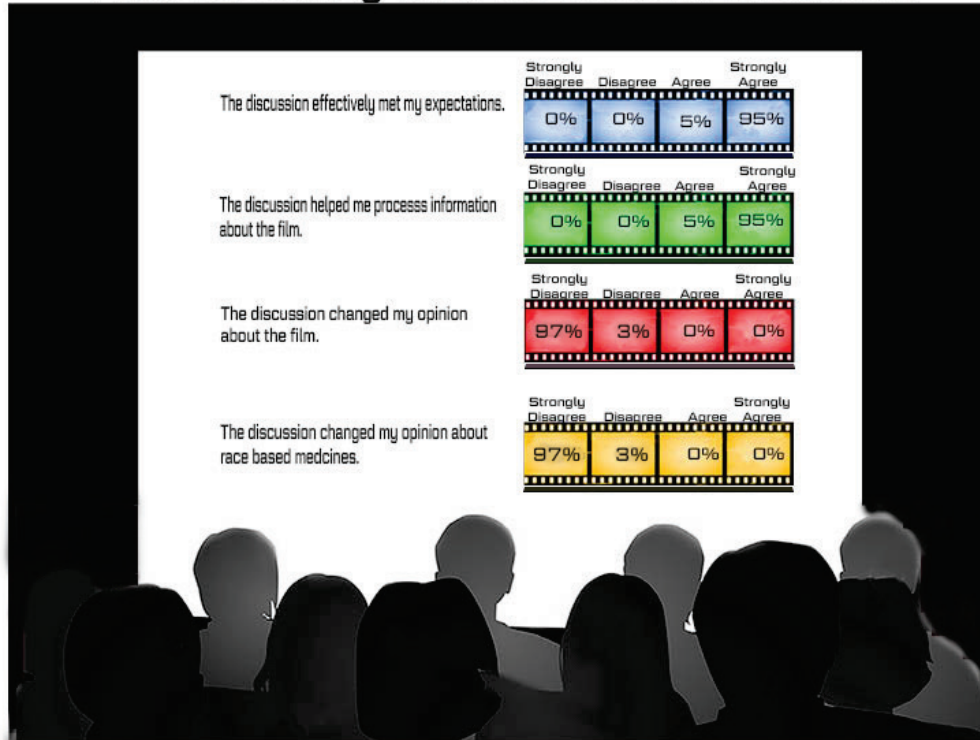


Table 3. Film Screening and Discussion Evaluation

Results from the Film Screening and Discussion Evaluation Form (Appendix G) were somewhat mixed. A great majority of participants, 95% in fact, selected *strongly agree*, to the first two questions. Clearly these results indicate the majority of the participants were aided by the discussion. However, when it came to participants having their opinions *changed* by the focus group (referenced in the third and fourth questions), the vast majority of participants selected *strongly disagree*. In fact, 97% of the participants indicated the focus group discussion *did not* change their opinions. I was actually very pleased to discover these results. The purpose of the focus group was to view the film together, but not necessarily to become a tool for changing opinions. I was pleased to know my viewers held fast to their own opinions, and did not allow opposing views from within the focus group, to sway them.

## **Results of Focus Group Interviews**

Prior to screening *The Colored Pill*, eight focus groups, with a total of 38 participants, took part in the focus group interviews. The average age of the focus group participant was 37. An overpopulation of African American participants was present.

The results from the focus group interviews indicate the film performance, *The Colored Pill*, did have significant effects on the advancement of knowledge, as was my motivation in making the film.

While information gained from the Pre- and Post- questionnaires was valuable in understanding a bit about my participants, that information was only the first step. In order to gain a fuller and deeper understanding of the ways in which the film advanced knowledge, I relied heavily on collected audio recordings, and thus transcript data, to examine the discourse of focus group interviews. The transcript data allowed me to closely examine how my participants engaged with the film.

A cross-analysis of focus group data, from both the questionnaires and the interviews, indicate that in terms of the film, participants felt their knowledge of race based medicines had been raised. Of significance here are the results from an analysis of the focus groups transcript data.

The great majority of focus group participants indicate *The Colored Pill* informed their knowledge about race based medicines. Participants spoke favorably about the film, and shared comments like, “*I definitely know now what I never knew was even happening.*” More to the point, one participant indicated:

*If I had not seen The Colored Pill, I would still be ignorant as a post. It's so strange how you can think you know all there is to know about your own history, and then find out that you don't. It's about time I got a real education in my own history.*

Notably, at the start of the focus group interviews, many participants shared a general skepticism about the health profession, but admitted they did not previously have hard or fast reasons for their feelings. After viewing *The Colored Pill*, this changed. Participants said they had an increased knowledge about both race based medicine (leading to their skepticism), and increased knowledge about BiDil®. They could define, with examples, what race based medicine is, and could also describe many racially targeted incidents of the past. Many participants, acknowledging their newly increased knowledge, expressed an interest in learning even more about other instances of race based medicine, not depicted in the film. Participants spoke at length about how they planned to educate others in their families and communities, and how they planned to remain vigilant for instances of racialized medicine in the future. It was clear to me that now that the participants were aware; they wanted to stay in the loop of knowledge.

In sum, analysis of both questionnaires and transcript data from this study clearly indicate the film performance affected knowledge about race based medicine. Nearly every participant reported that viewing *The Colored Pill* increased their knowledge of race based medicines. A very small minority of participants stated they had already received information about race based medicines, prior to the interview, however even those participants shared *The Colored Pill* reaffirmed knowledge they already had. I was

gratified by these results which provide new insight into the performance of film to elevate knowledge.

As a result of this study, several conclusions can be drawn. First and foremost, without exception, focus group participants had rarely been exposed to a film about race based medicines. Many participants had never been exposed to any media regarding racialized medicine. As one participant stated, *“This is the first I’ve heard of anything related to race based medicine.”* That means there is plenty of room for additional racialized medicine studies. Second, as a result of this film, participants were more than happy to have their knowledge elevated on the topic. One could conclude that participants of color have a built-in interest in this subject that currently is not being satisfied in the media. Again, this points to a possibility for future studies.

Additionally, during focus group interviews, participants began to investigate the messages contained in the film very deeply. It became increasingly important to the groups to talk about the shared meaning of racialized medicine. The film performance created a safe space for discourse to take place, and the passion in the dialogue of the participants indicates this was a process that did not happen often. Clearly, participants enjoyed speaking openly on this particular racialized topic. In particular, the results show that film performance is a good tool for testing information, specifically information about racialized medicine. The results show this study provided significant insight into the relationship between self-identified racial groups in focus groups, in-depth knowledge, and race based medicines.

This qualitative study has provided significant insight into whether a film performance could affect knowledge of race based medicines and treatments, however, it was without some limitations. In my final chapter, I share some of those limitations, as well as a few implications for the future.

## Chapter Seven. Giving Up The Ghost

Perhaps one day, when we have given up on letting technology determine our evolution, we might look back and shake our heads at the futility of racism. I hope, on that day, we scratch our heads in wonder at all the unimaginable ways we have caused pain based on little more than the color of skin. It takes the shine right off our boots to think of it. It is even harder to speak on it. But, we must. I began this study by sharing a powerful, destabilizing story called, *Christmas Eve* (Galeano, 1992). The story whispers of a young boy—a patient padding through the lonely corridors of a children’s hospital and who, through the isolation of his pain and suffering, made one final request, “*Tell someone I’m here*” (Galeano, 1992, p. 72). So much is said in those dying words, and yet so much is left unspoken. Is it so unusual? Most of us want the same thing as that young boy, padding through a hospital in his socks. We all want someone to know we are here. “*I am here in the world among you*” (Madison, 1998, p. 173). That which has a mouth wants to be heard. Even those who no longer have a mouth, or a body, for that matter, have a story that yearns to be heard.

I also began this study by focusing on another topic, of which, most can agree; the world is changing. When the red sky dims over the twilight bayou, still prowling the shores are those who have been ghosted—silhouettes and apparitions of those who have been forgotten by most. But this study is not just a metaphor, and those are not just phantoms standing on a lapping shore. Besides, I know them now. You do not need to hire a



Cessna, and soar 5,000 feet above the stormy waters of the United States, to see that changes are taking place up over yonder. Changes are taking place just a hop-skip-and-jump from whatever has captured our attention at the present moment. That said, time is a funny thing, isn't it? Ever notice that after a certain age, the future arrives so much sooner than anticipated? Paradoxically, shadows of the past, like unwelcome houseguests, seem to never leave. In this study I explored the shadows of our collective past. I acknowledged the spectral presences that haunt this research, and that haunt this nation—all metaphorical, of course. I recognize that those haunted faces, no matter how dim or how bright, cast shadows, and that those shadows come to be viewed as monsters and ghosts who still want to be heard. Those narratives still need to be heard.

It was fitting that I started this research with a discussion about faces, shadows, and bodies of color, because when you look around the globe there is a commonality taking place—a distinct browning is happening—and yet all the while, the human body remains very much the same. This quandary of being different and yet the same, is one we have reckoned with for eons. It is the reason Marco Polo and Swedish botanist Carl Linnaeus called humans who dwelled on the edges of the world, *homo sapiens monstrous*, instead of just, *us*. This study is not of the strange or the odd, unless you think of Marco Polo, Linnaeus, and even the creators of the drug BiDil® as monstrous—and more than that, as human monsters. I certainly do.

This is a study about mortal humans, in possession of many gifts including quite visible and distinct variations in color of skin, texture of hair, and body shapes. And while those divisions are visible, this is also a study about those things that are *invisible*.

Invisible wounds. Invisible, itchy and septic wounds that accompany racial distinctions. Invisible wounds that create visibilities like racism, inequalities, and surprisingly even visibilities in medicine. These oozing wounds run so deep and have festered so greatly, that the latest greatest potion, tonic, or pill cannot reach them. And, the deepest wound of all comes from the medicine itself, the so-called medicine that actually reifies race. In this study, that strange and odd medicine is known as BiDil®.

These sorts of strange and odd medicines were made visible in my history film performance, *The Colored Pill*. In this study, I focused on situating film audiences to peer into our collectively dark, medical history and see the face of the monster. I transmitted deep knowledge about the human monster, through the lens of history. Because my focus was on a race specific medicine, I was compelled to raise consciousness and knowledge about the monster in an intellectual and compelling way. And once I accomplished those things, and they were significant things to accomplish, I needed to learn how the film would affect audience viewers.

I designed this study as a type of ghost tour of medicine, medicine and/or medical treatments dispensed or withheld from bodies of color. Medicine or medical treatments that morphed humans into guinea pigs. Medicine, with a therapeutic purpose to prove difference. Fast forward to results of the Human Genome Project when (Lander, Linton, & Birren, 2001; Venter, Adams, & Myers, 2001) announced that, regardless of race or ethnicity on the level of our DNA, humans are amazingly similar. What continues to vex is that ironically, it is the infinitesimal *differences* locked inside our DNA, that scientists are interested in probing. Rewind back to the purpose of withholding medicine from

Black patients in the Tuskegee Syphilis Study, which was to document the idea that syphilis was a different disease in Blacks (Jones, 1993). Bounce back to 2005, when the creation of BiDil® was designed to document the idea that heart failure was a different disease in Blacks than it is in Whites. Make no mistake, heart failure is an important issue, but for goodness sakes, does the ill body care about race?

In the introduction to this study, I shared that the ill body speaks in two voices. One voice is biological, but the other is biographical. Deeply embedded in race specific drugs is the belief that there is a biological basis for race. This belief exists despite evidence to the contrary. In the film, *The Colored Pill*, many of the biological bodies have long since crossed over. That left their biographical bodies behind to tell their monstrous narratives of health. It is because monstrosity exists in the world, and specifically, in the world of medicine, that monstrousness became an embedded element in my research.

The purpose of this research was to contribute to a body of knowledge regarding our shared history of the past, and what Foucault (2003) might call *histories of the present*. My aim was to bring to light the human experiences surrounding racialized medicines, and also to intensify the knowledge of audience viewers about BiDil® and other racialized medicines/treatments. In so doing, my motive was to build on the ongoing research about BiDil®. As a filmmaker, my intention was to add to the body of research on history films—a term that James Chapman (2009) shares, “is not ‘real’ history, but a constructed version of history that accords with the ideological values of its makers and the cultural tastes of its audiences” (p. 7). With a performance lens, this study

aimed to inform and build on a new, innovative foundation for social inquiry. In this study, I uncover that a film performance can intensify knowledge about heart failure drug BiDil®, and also about other race specific pharmaceuticals and treatments.

Guiding this study is the research question: How does a film performance function to affect knowledge of race based medicines? Clearly, with that question in the forefront, there were two components—film performance and race based medicines that needed exploring. However, since the drug BiDil®, primarily targets African Americans, and my film performance also primarily targets the same racial group, I included *African Americans* as a third, *implied* element of analysis.

## **Summary**

The first chapter of this study linked the topic of race to the science of pharmacogenomics—how genes that represent racial differences can impact drug responses. That first chapter included an identification and overview of the significance of focusing on a pharmaceutical for cardiovascular disease. I shared the total annual cost for health care and lost productivity due to cardiovascular disease in the United States as being \$448 billion dollars (Flack, 2009, p. 52). I further shared that the National Heart Lung and Blood Institute (NHLBI) put heart disease at the top, costing \$296 billion in direct health expenditures, \$38 billion in indirect cost of morbidity, and \$114 billion in indirect cost of mortality (NHLBI, 2007). While heart disease continues to be the leading cause of death in the United States, for African Americans the prognosis is particularly troubling. The significance of this study points to the fact that heart failure affects African Americans more than any other group. Though not the rationale for film

performance addressed in chapter two, in this first chapter I discussed why I created a film performance, as the risk of dying from heart disease is 1.3 times higher in African Americans than to U.S. Whites (Mensah et al., 2015).

Chapters two and three highlighted the particular way of knowing I called on for this study—performance. I explained my positionality, as an African American filmmaker, and as a qualitative, performance studies scholar. I offered how, with that positionality, I am most interested in the voices of the underserved, the socially disadvantaged, and the economically oppressed people who stand in the shadows and along the shore.

The literature review in chapter two examined scholarship on history films, particularly those films made and analyzed by historians. That chapter also examined scholarship on film performance, where I argued four primary areas of film scholarship: literature on history films from a historian perspective, the impact of history films on knowledge, history film performances from a communication perspective, and history film performances about race based medicines. Chapter two also argued for the blending of film performance from a historians' perspective, with film performance from a communication perspective.

Moving on to chapter three, I covered the current dearth of performance resources to assist research film scholars in elevating knowledge about racialized drugs in the United States. Chapter three built on the inspiring research of Dr. Dwight Conquergood and Dr. Soyini Madison. Inspired by Dwight Conquergood, chapter three argued against the use of *textualism*, a long standing and dominant way of knowing. Dwight

Conquergood inspired my work because of his foundational consideration of research alternatives, such as filmmaking, as opposed to research centered solely in texts.

Conquergood's performance as epistemology framework provided me with a clear approach to meaning-making. His focus on interviewing and initiating conversations as methodology are techniques I embraced in my film creation, and also in my focus group interviews. Equipped with a common epistemological view, I saw Conquergood's work in performance as an excellent theoretical and methodological frame for my research.

In a similar vein, Dr. Soyini Madison's fervent performance ethnography work was equally inspiring to this study. In chapter three I put this inspiration to use, incorporating events of racialized medicine from our past and present histories, and placed them into a film performance in the current study. In chapter three I present D. Soyini Madison as the kind of scholar who used performance in an exemplary way, not just as an approach to inquiry, but as a methodology for collaborative meaning-making. I was heartened by the way Madison interrogated not only the past, but in the way she honored that past by allowing those narratives to come forward. I mimicked this in my study, using film as a counterhegemonic performance to challenge race based medical inequities.

The intersections of the film performance work of scholar Dwight Conquergood, along with the critical ethnographic work of scholar D. Soyini Madison, provided critical direction for this qualitative study. Chapter three appreciates how the writings of D. Soyini Madison and Dwight Conquergood saw performance as a backbone to both theoretical and methodological work. In this regard, I drew from both scholars and

positioned my history research film performance as both a theoretical and methodological tool. As epistemology, film performance is an approach to meaning-making. Therefore, meaning emerged from the performance tool itself. Chapter three further explained that as a pedagogical tool, *The Colored Pill* provided a unique perspective for meaning-making.

Chapter four concerned itself with the homo monstrous, the dark performance of horror. It was Nietzsche (1973) who said, “When you gaze long enough into an abyss the abyss also gazes into you” (p. 84). Therefore, chapter four made observations on how monstrosity was methodologically crucial to my argument. Because a part of this research was the creation of film, *The Colored Pill*, chapter four also demonstrated the relationship of monstrosity to a horror film. With this theme, I covered monstrosity from several viewpoints; monstrosity as medicine, monstrosity as race based medicines, and monstrosity as scientific racism.

What was particularly compelling for me about chapter four was my exploration of *sound as monstrosity* and *music as monstrosity*. As a filmmaker, I deepened the conversation about sound and music, that either creates the monster, or sound and music as an indication of the malevolent threat of the monstrous. Consequently, in chapter four, I examined film sound and music as devices of fear.

Chapter five ducked behind the scenes to discuss how I went from research to writing, producing, and directing the 70-minute film, *The Colored Pill*. In this chapter, I presented how the drug, BiDil®, became the inspirational spark for my study, and how the pharmaceutical haunted my imagination. I shared literature about the importance of

storytelling within racial/ethnic communities (Houston et al., 2011; Larkey & Hecht, 2010; McQueen, Kreuter, Kalesan, & Alcaraz, 2011; Robillard & Larkey, 2009; Unger, Cabassa, Molina, Contreras, & Baron, 2012). As a member of the African American community, I draw on storytelling in film performance. In chapter five, I entered an arena of debate, which called into question the methodological use of film to represent the past, while at the same time presented my film performance as a new paradigm to unlock information about BiDil®. Closing out chapter five, I continue in the vein of *The New York Times*' *Anatomy of a Scene*, as I deconstruct *The Colored Pill*. In this connection, I essentially slow down my film for interpretation and explanation of several pivotal scenes.

Chapter six explained my research design and method. I revealed why I chose a qualitative inquiry. I disclosed that as important as was the creation of the film, *The Colored Pill*, the film itself did not represent the data to be collected for this study. Instead, the data was the transcript discourse that took place from focus group interviews following the screening of the film. The qualitative results of this study were significant because the units of analysis were the actual words, phrases, and sentences extracted from transcript data.

Chapter six covered how my data collection method actually created two sets of data to analyze—questionnaires and focus group interview data. Both sets of data allowed me to examine my films' performance. In addition, chapter six outlined the dynamics of focus groups, and explained why I chose to examine interview discourse and group questionnaire responses through this research method.



In chapter six, I also examined the impact of *The Colored Pill* through a content-oriented approach to focus groups. Data for this qualitative study was collected via audio recorded, semi-structured focus group interviews. I shared how with audio taping, I was able to closely examine focus group interactions as a discursive practice.

Chapter six also explained that, due to the films' subject matter, focus group participants were primarily made up of members from the African American community, and/or other communities of color. I knew that with a shared history, African American focus group participants would be well positioned to provide their views on the subject of racialized medicine, particularly those pharmaceuticals targeted specifically to that community.

In chapter six I shared how this study is grounded in a deductive coding approach, which allowed the tenets of McGuire's (1985) information processing model to be integral to analyzing discourse from my focus group data. Chapter six articulated my method of data analysis as the transcription of focus group audio recordings. I explained how I created a custom-designed, deductive coding method for data analysis. In so doing, I analyzed only the transcript data (focus group discourse) that was directly relevant to and showed an in-depth understanding of racialized medicine. To do so, chapter six explained how I utilized McGuire's (1985) approach to information processing which involved four codes: exposure, attention, comprehension, and acceptance aka yielding.

Results from this study reveal the majority of my focus group participants, and thus, audience viewers of the film, were 79% female and 21% male. Results further reveal that participants in this study were made up of 30 females and eight males. Results

also indicate the racial/ethnic make-up of participants, 95% of participants self-identified as a person of color. Specifically, 63% of participants in this study were African American, 26% Hispanic/Latino, 5% Asian, 3% Multi-Racial and 3% White/Caucasian. Participant ages ranged from 18 to 69, the average age being 37.

Results from the analysis of this study show that 66% of participants held high school diplomas or GEDs, 16% of participants indicate some college/university, 13% of participants report having earned an Associate Degree, 3% of participants indicate having a Bachelor's Degree, and 3% indicated having a Graduate Degree.

An analysis of the top five genres of films participants of this study generally like to watch revealed: 39% chose Adventure, 32% chose Action, 29% selected Drama, 26% picked Comedy, and 13% prefer Horror.

Comparative results, between the Pre-Awareness Survey, administered *before* the film screening, against the Post-Awareness Survey, administered *after* the film was screened, could not be starker. Prior to film screening, results indicate that 100% of participants were *not aware of race based drugs*. However, after screening *The Colored Pill*, the majority of participants (97%) indicate they had *a lot of knowledge* on the topic. These results show the film moved the continuum of knowledge quite significantly—from *not aware* to having *a lot of knowledge*. Further, after the film screening, participants were asked to define race based medicine in their own words. An overwhelming majority of participants could provide a definition. For these reasons, chapter six had an interesting quantitative result. After administering a one-tailed, paired-samples t-test, participants' average level of knowledge of race-based medicines was

greater after viewing the film ( $M = 8.89$ ,  $SD = .51$ ) than it was before viewing the film ( $M = 1.03$ ,  $SD = .16$ ).

Chapter six also had another post-screening result, this time, from a final questionnaire called Film Screening and Discussion Evaluation. Results from this questionnaire indicate the focus group discussions both met participant expectation, and helped participants' process information about the film. A cross-analysis of focus group data from questionnaires and interviews indicate that participants in this study felt their knowledge of race based medicines had been raised. In addition, when I relied heavily on just the transcript data from this study, participants revealed the film significantly affected their knowledge on the topic.

Chapter six explained how my custom-designed, deductive codes—*exposure*, *attention*, *comprehension*, and *acceptance*—were used in data analysis to indicate the acquisition of participant knowledge. Using these four pre-designed themes, results of this study indicate the participants could provide numerous real-world examples of knowledge inroads. Since this study of discourse analysis needed only to analyze those parts of the discourse that supported the four codes of data analysis, participants clearly shared the film had a positive effect on their knowledge of race based medicines.

The final, overall significant contribution of the current study is the degree to which participants indicated *The Colored Pill* informed their knowledge about race based medicines, and spoke favorably about the film itself. Clearly, this study met its goal of using *The Colored Pill* film to affect knowledge of race based medicines. Results from this study demonstrate the importance of producing history films to affect knowledge.

Overwhelmingly, focus group participants who came into the film screening with little to no knowledge of racialized medicine left the screening with a noticeable increase in knowledge. Though results of this study overwhelmingly point to the advancement of knowledge, limitations must be considered.

### **Limitations**

While the results of analyzing the film, *The Colored Pill*, were tremendously positive, in having only one film to analyze, I cannot present a multi-layered, historical analysis. Another limitation of this study points to the fact that I called on a relatively small sample size of individuals, who all live in the same geographical area. In so doing, I am limited from exploring the views held by a variety of individuals who live and dwell in other geographical areas.

Primarily, this study focused on my assumption that deductive coding analysis of four pre-defined themes, provided a good lens for focus group discussion. While this coding approach provided a solid platform for discourse analysis in the focus group process, I also might have looked into other approaches. Narrative theory might have provided a good approach for both examining the film, and in studying the stories that focus group participants shared in their interviews.

While film performance presents a fresh, new perspective for meaning-making, one limitation to film points to concerns the public may have about the accuracy of the topic. Though inspired by true events, *The Colored Pill* was presented as a work of fiction. Important questions may arise about the truthfulness of the film and

consequently, the film may be seen as just entertainment, rather than the tool for knowledge elevation, as it was intended.

While this is one of a few studies to demonstrate effectiveness of a film performance in advancing knowledge, there is no information in this study related to how much of the films' information will be retained. Future evaluations might randomly select participants to study whether knowledge of race specific medicines is sustained. Further studies will be needed to understand both short- and long-term knowledge retention, as well as what effect, if any, the film has on behavior.

### **Suggestions for Future Research**

The results of this study point to several implications for the future. The most obvious limitation in this study is the relatively small sample size. In so doing, I am not considering the opinions of those who may live in another part of the country. Therefore, it would be interesting to know how dissimilar individuals, who live in different geographic areas, and who possess different backgrounds, might fare in this study.

This study described pharmacogenomics and racialized illnesses as sites of pain and suffering, but the world of health is hardly a utopia. This study does not look into under what specific conditions race should be used as a variable in the world of health. Somewhat related, this study does not address whether the use of pharmacogenomics research is completely going in the wrong direction, or if it only seems that way because race is used to support differences.

In the future, communication scholars should join up with genetic scholars to examine other issues related to socialized drugs, including gender and/or class.

Intercultural scholars may want to look at how race specific pharmaceuticals fit into the larger global picture related to racial categories and identities. Intercultural scholars may also be interested in studying racial and ethnic discrimination based on medical research.

While *The Colored Pill* was inspired by true events and supported by extensive research; the film is nonetheless, a work of fiction. While I maintain that very few film audience members blindly accept all information provided in any film, one method future filmmakers might use to ensure their film work is seen as more than just entertainment, is to utilize documentary filmmaking. With the credibility associated with documentaries, questions may not arise about the accuracy of their work, or about the medium chosen to disseminate knowledge to the public.

### **Final Remarks**

Until our grandchildren's grandchildren come of age, the story of race based medicine will, most likely, continue to be an unfinished tale. That said, it is my hope that in the future, the FDA will head off many bumps in the road. The FDA would be well advised to require all clinical trials to use statistically significant samples of diverse populations. If a diverse trial like that had been in place, prior to the approval of BiDil®, this study may have instead been on the flight patterns of the fruit fly.

Since the approval of BiDil®, race specific drug research has continued. Currently, *Crestor*, a cholesterol medication, has been found to be effective in self-identified Asian patients (<http://www.crestor.com/c/your-arteries/tools-resources/index.aspx>). *Crestor* has also conducted a race based clinical trial to study the drug's effectiveness in the Hispanic community. Similar race based results have been

reported between Asians and the Bristol Meyers pharmaceutical known as *warfarin*, a blood-thinning medication similar to the drug brand, *coumadin* (Kahn, 2012). Another medication, *veliflapon*, has been associated with preventing heart failure, once again, in self-identified African American patients (Hakonarson et al., 2005).

In closing, one may wonder what has happened to BiDil®. NitroMed Inc., the owners of BiDil®, changed hands from Deerfield Management (in a \$36 million acquisition) to its 2013 owner, Arbor Pharmaceuticals, Inc.—a U.S.-based specialty pharmaceutical company. The amount of that acquisition is unknown. What *is* known is that in March, 2019, Arbor Pharmaceuticals announced the launch of the *Shaquille Gets Real About Heart Failure* campaign—a national, educational maneuver to raise awareness about the disparity of heart failure in the African American community. Though he does not have heart failure himself, Shaquille O'Neal (Shaq), is recognized around the world as a celebrity basketball hall of famer. Shaq has partnered with Arbor Pharmaceuticals to spread the word that African Americans need to take heart failure seriously; however, this is hardly Shaq's first advertising job. Making far more money in endorsements than he ever did on the basketball court, Shaq has backed many products such as: Zales, 24 Hour Fitness, Muscle Milk, Dove For Men, Comcast, Buick and Icy Hot. He has also served as the peddler for Pepsi, Wheaties, Reebok, Burger King, Carnival Cruise Lines, The General Insurance, Gold Bond powder, Epson printers, and of course, now BiDil®.

The race specific patent, covering the use of BiDil® in the general population, expires sometime in 2020.

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## APPENDICES

### APPENDIX A

#### **Sample Open Letter of Invitation for Focus Group Participation**

*University of Denver  
Social, Behavioral, and Educational Research  
Sample Open Letter*

#### **Sample Open Letter of Invitation for Focus Group Participation**

Welcome Participants,

You are invited to participate in a focus group discussion about race, identity, and race based medicines in the African American community. You are being asked to be a part of this research because you are a member of a racial group that has been identified as a target for race based medicines. The research will take about 1-1/2 to 2 hours, and will be held on \_\_\_\_\_ from \_\_\_\_\_ until \_\_\_\_\_ at \_\_\_\_\_ . Light snacks will be provided.

The Moderator for this focus group, Wanda Lakota, is currently conducting focus groups based on a newly created film on race. Wanda Lakota is a doctoral student in Human Communications at the University of Denver. This study is being conducted to fulfill degree requirements. The goal of this focus group is aimed at raising awareness about race based medicines.

If you agree to participate, you will be asked to view a free film, and share your thoughts and opinions about race, identify and race based medicines. As a participant in this focus group, your views and experiences are extremely valuable in helping meet the goals of this research study. You should know that others in the focus group will hear what you say, and it is possible that they could tell someone else. Since we will be talking in a

group, we cannot promise that what you say will remain completely private, but we ask that you and all other group members respect the privacy of everyone in the group.

As part of this research project, we will be taking an audiotape recording of your participation in the study. Your name will *not* be identified.

The researcher has taken steps to minimize the risks of this study. Even so, you may still experience some risks related to your participation. Identified risks may include emotional discomfort from answering surveys or interview questions. The probability of harm and discomfort from those identified risks will not be greater than in a daily life encounter. The study may include other risks that are unknown at this time.

You will not be charged for any part of the study. You will not be given any reimbursement for your time and/or travel expenses.

Although we hope you will join us, participation is voluntary. You are under no obligation to participate, and there will be no negative consequences if you withdraw. We hope that you will be able to join us for this important discussion.

I will be happy to answer any questions you have about the study. You may contact me at (303) 871-2385 or at [wandalakota@gmail.com](mailto:wandalakota@gmail.com), if you have study related questions or problems.

## APPENDIX B

### Informed Consent



**Approval Date:**

**Valid for Use Through:**

#### University of Denver Consent Form for Participation in Research

**Title of Research Study:** THE COLORED PILL: A FILM PERFORMANCE PROJECT

**Researcher(s):** Wanda Lakota, PhD Candidate, University of Denver  
Dr. Bernadette Calafell, Faculty Sponsor, University of Denver

**Study Site:** Conference rooms, Meeting rooms, Private residences

#### **Purpose**

You are being asked to participate in a research study. The purpose of this research is to study race, identity, and race based drugs. You are being asked to be in this research study because you are a member of a racial/ethnic group that has been identified as a target for race-based medicines. You were also selected because you are familiar with issues involving racial/ethnic groups.

#### **Procedures**

If you participate in this research study, you will be invited to arrive at a pre-selected venue, which will be provided to you. You will be asked to fill out several surveys, watch *The Colored Pill*©—a film performance, and participate in a focus group. The research will take about two hours, and will take place on one day. The approximate number of subjects in this research study is 16.

#### **Voluntary Participation**

Participating in this research study is completely voluntary. Even if you decide to participate now, you may change your mind and stop at any time. You may choose not to answer any survey question or continue with the focus group interview for any reason without penalty or other benefits to which you are entitled. If you decide to withdraw before being audio taped, the information or data you provided will be destroyed. If you

decide to withdraw after audio-taped recordings have begun (after Informed Consent form has been signed and turned in), the information or data you provided cannot be destroyed because audio taping would have already begun.

### **Risks or Discomforts**

Potential risks and/or discomforts of participation may include emotional discomfort from answering surveys or focus group interview questions. Risks may include the discomfort of having your views challenged by others in a focus group, embarrassment, and/or loss of privacy. The probability of harm and discomfort from those identified risks will not be greater than in a daily life encounter. The study may involve risks to participants that are currently unforeseeable.

### **Benefits**

Possible benefits of participation include allowing the researcher to learn more about race, identity and race based drugs, as well as whether film can raise awareness. While there may be no direct benefits for you, your engagement in this research study creates the potential for advancing theory and practices in relation to race and identity. Specifically, this study potentially can provide key insights about the experiences of communities of color and address the impact race based medicines may have on these communities. If you agree to take part in this study, there may be no direct benefit to you; however, information gathered in this study may help the researcher understand current awareness levels related to race based drugs as well as whether film can raise awareness.

### **Incentives to participate**

You will not receive any compensation, reimbursement, or incentive for participating in this research project.

### **Study Costs**

You will be expected to pay for your own transportation, parking, or child care, if needed.

### **Confidentiality**

The researcher will ensure that your name will not be attached to any data. Instead, a study number and/or pseudonym will be used. The data you provide will be stored in a secure, locked file cabinet. The researcher and research team will retain the data for five years to keep your information safe throughout this study. Your individual identity will be kept private when information is presented or published about this study.

The results from the research may be made available to other researchers for other studies, but will not contain information that could identify you (de-identified). Individual identities will be kept private when information is presented or published.

Only the researcher will have access to the original data (audio), while stored. If recordings are uploaded, all electronic data (laptop or computer) will be password protected onto a computer without Internet connection. Original data will be destroyed after five years.

Since this research includes focus groups, minimal identifying information will be gathered during the focus group meetings. A code and/or pseudonym will be given to each focus group participant. Audio recordings will be uploaded to a password-protected file located on the personal server of Wanda Lakota and accessible only by passcode by Wanda Lakota or members of the research team. Transcriptions of the focus group meetings, which will be completed by Wanda Lakota and/or research team, will take place via a software program. Transcriptions will be retained and stored in a password-protected computer without Internet connection. During transcription, participant names will be redacted and coded with label codes and/or pseudonyms. Data will be retained for five years after data analysis has been completed. After five years, all recordings and materials will be destroyed. The key to participant identities and code lists will be stored in a separate, secure, and locked file.

The researcher reminds focus group participants to respect the privacy of fellow participants, and asks that they not repeat what is said in the focus group to others. Please be advised that although the researcher will take every precaution to maintain confidentiality of the data, the nature of focus groups prevents the researcher from guaranteeing confidentiality.

However, should any information contained in this study be the subject of a court order or lawful subpoena, the University of Denver might not be able to avoid compliance with the order or subpoena. The research information may be shared with federal agencies or local committees who are responsible for protecting research participants.

### **Questions**

If you have any questions about this project or your participation, please feel free to ask questions now or contact Wanda Lakota at (303) 871-2385 and/or [wandalakota@yahoo.com](mailto:wandalakota@yahoo.com) at any time. The Faculty Sponsor/Advisor at the University of Denver is Dr. Bernadette Calafell. Dr. Calafell can be reached in the Department of Communication Studies at (303) 871-4322.

If you have any questions or concerns about your research participation or rights as a participant, you may contact the DU Human Research Protections Program by emailing [IRBAdmin@du.edu](mailto:IRBAdmin@du.edu) or calling (303) 871-2121 to speak to someone other than the researchers.

### **Focus groups**

This research involves focus groups. In the focus group, the researcher will invite individuals to meet together to discuss their opinions and perceptions of a film

performance. The discussion questions include your reaction to the film, how you define race based drugs, what you know and do not know about race based drugs, as well as how the film effects your awareness of and opinion about race based drugs.

The focus group will be audio recorded. De-identified focus group data may become part of a larger media project (future research studies, educational purposes, etc.) Focus group recordings and transcripts will be kept in a secure and locked cabinet with access limited to Wanda Lakota. To protect the privacy of focus group members, all transcripts will be coded with a study number and/or pseudonym. All original data will be destroyed after five years.

### **Audio Recordings**

Audio recordings of the focus group will begin once complete and signed Informed Consent Form has been turned in. If you do not agree to be audio taped, you are not eligible to participate in this study. In audio taping, focus group language choices (discourse) and social interaction processes will be analyzed, as well as tacit knowledge (unarticulated understandings demonstrated in nods and non-verbal nuances). In the data analysis phase of the design work, the audio recordings will be reviewed and transcripts will be reread to uncover social interactions, experiences, and actions that may have previously been overlooked.

### **Audiotape Recording Data**

Following the making of the audio recordings, the original data will be kept for five years. The recordings will be stored in a locked file cabinet and linked with a code and/or pseudonym, to subjects' identity. To keep your information safe, your name will not be attached to any data. Only the researcher will have access to the original data, while stored. The original data recordings will be destroyed within five years after data is collected. Results from the research may be shared at meetings and within public forums. Results from the research may be shared in published articles. If the results from the research are used for commercial purposes, you will not be compensated for this use.

As a part of this study, the de-identified audio-tape recordings:

- can be studied by the Researcher and research team for use in the research project.
- can be used for publications.

### **Confidentiality, Storage and Future Use of Data**

The researcher will ensure that your name will not be attached to any data. Instead, a study number and/or pseudonym will be used. The data you provide will be stored in a secure, locked file cabinet. The researcher and research team will retain the data for five years to keep your information safe throughout this study. Your individual identity will be kept private when information is presented or published about this study.

The results from the research may be made available to other researchers for other studies, but will not contain information that could identify you (de-identified). Individual identities will be kept private when information is presented or published.

Only the researcher will have access to the original data (audio), while stored. If recordings are uploaded, all electronic data (laptop or computer) will be password protected onto a computer without Internet connection. Original data will be destroyed after five years.

Since this research includes focus groups, minimal identifying information will be gathered during the focus group meetings. A code and/or pseudonym will be given to each focus group participant. Audio recordings will be uploaded to a password-protected file located on the personal server of Wanda Lakota and accessible only by passcode by Wanda Lakota or members of the research team. Transcriptions of the focus group meetings, which will be completed by Wanda Lakota and/or research team, will take place via a software program. Transcriptions will be retained and stored in a password-protected computer without Internet connection. During transcription, participant names will be redacted and coded with label codes and/or pseudonyms. Data will be retained for five years after data analysis has been completed. After five years, all recordings and materials will be destroyed. The key to participant identities and code lists will be stored in a separate, secure, and locked file.

The researcher reminds focus group participants to respect the privacy of fellow participants, and asks that they not repeat what is said in the focus group to others. Please be advised that although the researcher will take every precaution to maintain confidentiality of the data, the nature of focus groups prevents the researcher from guaranteeing confidentiality.

However, should any information contained in this study be the subject of a court order or lawful subpoena, the University of Denver might not be able to avoid compliance with the order or subpoena. The research information may be shared with federal agencies or local committees who are responsible for protecting research participants, including individuals on behalf of Dr. Bernadette Marie Calafell.

#### **Who will see my research information?**

Although the researcher will do everything she can to keep your records a secret, confidentiality cannot be guaranteed. Both the records that identify you and the consent form signed by you may be looked at by others

- Federal agencies that monitor human subject research
- Human Subject Research Committee

All of these people are required to keep your identity confidential. Otherwise, records that identify you will be available only to people working on the study, unless you give permission for other people to see the records. Also, if you tell us something that makes



us believe that you or others have been or may be physically harmed; we may report that information to the appropriate agencies.

**Significant New Findings**

Significant new findings developed during the course of the study, which may relate to your willingness to continue participation, will be provided to you.

Audio recordings of the focus group will begin once complete and signed Informed Consent Form has been turned in.

**If you do not agree to be audio taped, you are not eligible to participate in this study.**

**Options for Participation**

Please initial your choice for the options below:

\_\_\_ The researchers may audio record me during this study.

\_\_\_ The researchers may NOT audio record me during this study.

Please take all the time you need to read through this document and decide whether you would like to participate in this research study.

If you agree to participate in this research study, please sign below. You will be given a copy of this form for your records.

\_\_\_\_\_  
**Participant Signature**

\_\_\_\_\_  
**Date**

## APPENDIX C

### Demographic Survey

*University of Denver*  
*Social, Behavioral, and Educational Research*  
*Questionnaire Protocol*

#### FILM SCREENING: Demographic Survey

**Your feedback is important. Please take a moment to provide some very basic demographic information about yourself. Please do not include your name.**

**How do you self-identify:**                      Male      Female

**What is your ethnicity?**  
\_\_\_\_\_

**How do you self-identify racially?**  
\_\_\_\_\_

**What is your age group?**    18-25      25-35      36-45      46-66      67-87  
Above 88  
(Circle one)

**Please indicate your highest level of education:**

Some High School	_____	
High School Diploma or GED	_____	
Some College/University	_____	
Associate's Degree	_____	Year? _____
Bachelor's Degree	_____	Year? _____
Graduate Degree	_____	Year? _____

**What types of film do you generally like to watch?**

You may circle more than one.

Action	Adventure	Comedy	Drama	Historical
Non-Fiction	Horror	Musical	Sci-Fi	Romance
Documentary	Other _____			

**How many documentaries have you watched in the past year?**

0                      1                      2-3                      4-6                      7-10                      More than 10

## APPENDIX D

### Pre-Awareness Survey

*University of Denver  
Social, Behavioral, and Educational Research  
Questionnaire Protocol*

#### FILM SCREENING: Pre-Awareness Survey

**Your feedback is important. To begin this research study, please take just a few minutes to complete this survey. Please do not include your name.**

**Have you heard of race based medicines? Circle one:**

Yes

No

**If so, where did you hear about it? What do you know about race based medicines?**

**On a scale of 1-10, how aware are you currently about race based medicines? On this scale 1 indicates that you are not aware of race based medicines at all (never heard of it) and 10 will indicate that you have a lot of knowledge about race based medicines (i.e., read articles, seen it discussed in other media, have held numerous conversations about it)**

1      2      3      4      5      6      7      8      9      10

**Had you ever heard of race based medicines, prior to today? If so, what have you heard?**

**What is your attitude toward race based medicines, if any?**

**What are your feelings about race based medicines, if any?**

## APPENDIX E

### Focus Group Interview Protocol

**Approval Date:**

**Valid for Use Through:**

**Project Title:**

THE COLORED PILL: A FILM PERFORMANCE PROJECT

**Principal Investigator:**

Wanda Lakota

**Faculty Sponsor:**

Dr. Bernadette Calafell

**DU IRB Protocol #:**

726284-1

1. Welcome, Rapport building, and Self Introduction (5 minutes)

*Notes To Interviewer: Begin this protocol once the majority of the participants have taken their seats.*

*Notes To Interviewer: Instruct participants to nearest exits and restrooms.*

Welcome. Good evening and welcome to our session. Thank you for taking the time to join me in a dialogue and screen a new film which examines race, identity, and race based medicines.

My name is Wanda Lakota. I am a doctoral student in the Department of Human Communication at the University of Denver. This research has been reviewed according to the University of Denver IRB procedures for research involving human subjects. This focus group is a part of fulfilling the requirements for my degree. I am hosting focus group discussions like this with several groups in Denver, Colorado. I want to know your opinions, what you know and do not know, about race based medicines. What I learn from today's, and others discussions, will be used to learn about awareness levels about race based medicines. What I learn from today's and others discussion will also become part of my dissertation.

You were invited to take part in this focus group discussion because you are a member of a racial group that has been identified as a target for race based medicines. You were also selected today because you are familiar with issues involving

	<p>racial/ethnic groups. Your participation in this research study is voluntary. You may choose not to participate. If you decide not to participate in this research, you may withdraw at any time. You will not be penalized in any way for withdrawing. You must be at least 18 years old to participate.</p>
2. Introductions, Additional rapport building - optional (6 minutes)	<p>Though you each have been given a code number to wear on your clothing, why don't we go around the room, starting on my right, and have each person briefly introduce him or herself. Please tell us your first name only, however, during the session, if you need to ask another participant a question or make a comment directly to someone, please refer to that participant by their code number, as it will be much easier for the coder to transcribe the audio tape.</p>
3. Ground Rules (6 minutes)	<p>In just a few moments, we are going to watch a film performance called <i>The Colored Pill</i>©. Before we start the film, I would like to go over a few of the ground rules for the focus group discussion:</p> <ol style="list-style-type: none"> <li>As you came in, you were asked to complete a short demographic questionnaire and pre-awareness survey. The questionnaire was completed so you could provide basic demographics—gender identification, age group, types of films you enjoy, and if you have watched independent films in the past year. The pre-awareness survey was designed to uncover what you currently know about race based drugs.</li> <li>As you came in, you were also asked to sign and hand-in your Informed Consent Form.</li> <li>Is there anyone present who has not handed in any of those three forms: the demographic questionnaire, the pre-awareness survey, and the Informed Consent Form? (pause). Ok, let's</li> </ol>
<p><i>Note To Interviewer:</i> <i>Pause here</i></p>	

continue. Since your Informed Consent Form has been signed, the audio tape will now be turned on, and recording will begin. If you did not sign your Informed Consent Form, you are not eligible to participate in this study. (pause). Ok.

- d. During the focus group, I will serve as your Moderator. This means that my job is to guide the discussion. As the Moderator, I am not the expert on the topic. As the Moderator, I am co-performing with you (rather than acting as a participant-observer) though not as a focus group speaker. My role is to honor and encourage all of you to interact and enter into a dialogue with each other . . . not necessarily with me. So please, talk to each other! Interaction between each of you is strongly encouraged. Feel free to ask each other for clarification and feel free to openly disagree with each other. My jobs as your Moderator is to encourage a dynamic discussion, help keep the discussion on task, and to be respectful of the time you have committed to give here.
- e. To that end, this focus group discussion will take approximately 2 hours.
- f. Please know that for this discussion, there is no right or wrong answer. There are only differing viewpoints. With that in mind, please feel free

*Notes To Interviewer:  
Pause here*

*Notes To Interviewer:  
Pause here to allow  
participants time to  
ask questions*

to share your viewpoint, even if they differ from others. For this research, I am interested in negative comments as much as positive.

- g. You do not need to agree with others' viewpoints, but I do ask that you listen critically and respond respectfully to each other.
- h. I am sure that you have noticed the camera, lights, and other equipment that has been set up in this room. Your signed Informed Consent Forms gives your permission for the audio taping of this focus group discussion. After your Informed Consent Forms were turned in, and audio recorders were turned on. So that you can be clearly heard, I ask that only one person speak at a time. I also ask that you refrain from interrupting each other.
- i. I also ask that you do not have side conversations, as those conversations as others will not be able to hear your comments and your comments will not clearly be picked up by the devices in the room.
- j. Regarding your cell phone, I ask that all cell phones be turned off, or placed on vibrate, during this focus group discussion. If you cannot turn off your phone and if you must take an important call, please do so as quietly



as possible and rejoin the group as quickly as possible.

Does anyone have any questions at this point?

4. Film  
Screening (70  
minutes)

I would now like to screen a new film, which introduces the topic of our focus group. The title of this film performance is, *The Colored Pill*©. I will not give the film any further introduction, as I believe the content will speak for itself. The film has a running time of 70 minutes. Immediately following the film, I will ask that you complete a Post-awareness survey. After that, we will begin our focus group discussion questions. I ask that you do not talk amongst yourself after the screening of the film, so as not to disturb other participants while they are completing their Post-awareness survey.

*Notes To Interviewer:  
Pause here*

Does anyone have any questions before we screen the film?

5. Break (10  
minutes)

We have two more topics to discuss today, but it's been about an hour. This might be a good place to stop for a quick break. So why don't you stand up, stretch your legs a bit, or have some more refreshments. If you re-introduce yourself to anyone during the break, please remember to only use your first name. When we return, we'll spend some time talking about how well the film did in raising awareness about race based medicines. After that, we'll tackle racialized identities.

*Notes To Interviewer:  
Begin reconvening  
group after 7 minutes  
have elapsed to  
ensure they are back  
by 10 minutes*

I ask that you please be mindful of the time, and I'll see everyone back here in just 10 minutes.

6. Group  
Discussion –

*Topic #1: (Performance) Raising Awareness*

Topic 1 (14 minutes)

*Notes To Interviewer:  
Tell participants this  
is the first of three  
topics for today*

Next, I would like to discuss how well the film raised awareness about race based medicines in the African American community.

- a. Did the film affect you? (Aesthetic merit question) How/In what ways?
- b. How was the subject of race based medicines portrayed in the film? (Interpretive view) Was it portrayed fairly? Did you detect a bias?
- c. How did this film help in terms of providing insight on how participants might act if race based medicines are prescribed to themselves or members of their families (Critical view).
- d. How do you feel about using race as a rationale for whom is better suited for particular drugs?
- e. Are you troubled by race based medicines, or the way race-based medicines are being played out?
- f. Should there be different drugs for different races?

*Optional Questions, only if time permits:*

- g. Were you offered new information and an unusual perspective to the topic?
- h. Was the film clear? Did the film have clarity? (Good qualitative research question)

PROBE IDEAS:

Pause

Does anyone have a different experience?

Can you tell me more about that?

7. Group  
Discussion –  
Topic 2 (15  
minutes)

*Notes to Interviewer:  
Tell participants this  
is the second of three  
topics for today*

Does anyone have an example they would like to share?

Anything else?

*Topic #2: Identity*

I would like to switch gears a bit and discuss racialized identities.

- a. How do you define African American?
- b. Which social categories of race do we place African American Arabs, or African American Latina/o Americans? Who are the closest genetic relatives for the Australian Aborigines?
- c. Which race do any of us truly ‘belong’ to?
- d. While the U.S. Census classifies races, after years of genetic intermingling, does anyone really know how much African American blood they have in their lineage?
- e. In order to support new advances in pharmacogenomics, should we reinstitute the old one drop rule for racial identification?
- f. Does a race based medicine have any effect on your racialized identity – the way you self-identify racially? If so, how? If not, why not?
- g. After watching the film performance, what does race based medicine *feel* like?  
(Artistic/Left-brain question)
- h. Is it important for members of your race to have knowledge of race based medicine? Why or why not?

- i. Might race based medicines create a positive, or negative (or both) toll on members of your culture? Explain.

PROBES IDEAS, *only if time permits::*

Pause

You look unsure of that comment. Why

Does anyone have a different perspective?

Why do you feel that way?

Anything else?

8. Group  
Discussion –  
Topic 3 (15  
minutes)

*Notes to Interviewer:  
Tell participants this  
is the last topic to be  
discussed for today.*

*During this topic,  
make sure there will  
still be 9 minutes for  
the debrief and wrap  
up at the end. If it  
seems there will not  
be 9 minutes left, cut  
this discussion short.  
In doing so, the total  
focus group time of 2  
hours will not run  
over.*

*Topic#3: Future Directions and Recommendations*

The last thing that I'd like to discuss with you is your ideas for the future. These questions ask you to reflect on your own experiences, or the experiences of members of your community. In that vein, you are asked to share recommendations you may have about the film or about these focus group discussions. When answering these questions, please reflect on your own, or members of your community experiences:

- a. What suggestions can you make that will help the film involve the viewer, rather than talking at them?
- b. Does the film seem like it will be "just another film" or is it something that people might want to tell each other about the next day? Why or why not?
- c. During the film performance, did you feel as though you were involved? Do you have suggestions on how the feel could have made

you, or members of your community, feel more involved?

- d. How can various other media contribute to raising awareness about race and race based medicines? Which media?
- e. If you had a chance to speak to some of the larger pharmaceutical companies, or to the agency that approved BiDil®, the U.S. Food and Drug Administration (FDA), what is the one thing you would want them to know about your thoughts on race based medicines? (Big-picture question)

PROBE IDEAS, *only if time permits::*

Pause

Does anyone have a different perspective?

Why do you say that?

Anything else?

9. Debrief (5 minutes)

Those were all the questions I prepared for today. I have just one short survey for you to complete, but before I do that, do you have any questions or anything else you would like to add to this discussion before we conclude?

PROBE IDEAS, *only if time permits::*

Pause

Anything else?

10. Wrap-up (4 minutes)

I would like to thank you all for your time today and for participating in this important focus group discussion. Your comments and opinions are vital to

my research, and I hope you enjoyed sharing them today.

I would like to remind each of you to respect the privacy of your fellow participants and not repeat what was said in the focus group to others. While I will take every precaution to maintain confidentiality of the data, the nature of focus groups prevents me from guaranteeing confidentiality.

If you would like more information on my dissertation, please leave me your email address and I will keep you informed on my progress.

Once again, thank you for participating.

*Notes To Interviewer:  
Try to say good bye  
to each participant,  
and shake their hand*

Ok, my Assistant will pass out the final survey: “The Colored Pill”

Film Screening and Discussion Evaluation Form . . . for you to fill out. Please give it to her/him as you leave.

Good bye.

Total Focus Group  
Time: 180 minutes

## Post-Awareness Survey

**FILM SCREENING: Post-Awareness Survey.**

**Please indicate your overall evaluation of today's film screening (circle number):**

**Was the film you watched about BiDil® a compelling and dramatic story?**

**Please provide a short answer to the following question. Your answer will help us understand how much the film raised your awareness. In your own words, what is race based medicine?**

**On a scale of 1-10, how aware are you currently about race based medicines?**

[illegible]

### OPTIONAL QUESTIONS ONLY:

## What is your attitude toward race based medicines, if any?

## What are your feelings about race based medicines, if any?



## APPENDIX G

### Film Screening and Discussion Evaluation Form

*University of Denver  
Social, Behavioral, and Educational Research  
Questionnaire Protocol*

#### **THE COLORED PILL: Film Screening and Discussion Evaluation Form**

Your final feedback is important. To assist me in providing the best possible screening and discussion, please circle the number corresponding to your assessment of this event. For each statement, please circle the number that you believe to be the most correct. Please do not include your name.

**1-Strongly Disagree      2-Disagree      3-Agree      4-Strongly Agree**

#### **Focus Group Discussion**

The discussion effectively met my expectations.      1    2    3    4

The discussion helped me process information about the film.      1    2    3    4

The discussion changed my opinion about the film.      1    2    3    4

The discussion changed my opinion about race based medicines.      1    2    3    4

#### **Film**

Watching *The Colored Pill* raised my race-based drugs awareness.      1    2    3    4

I would recommend watching this film to a friend.      1    2    3    4

It is important for members of my race to have knowledge of  
race based drugs.      1    2    3    4

**Additional comments about any aspect of the screening and discussion  
(film, moderator, focus group, materials, topics covered, etc.)**

## **APPENDIX H**

### **Complete Acknowledgements**

The last chapter in this study is called, Giving Up The Ghost. And that, I have done, though I have also kept the faith. Humbly I acknowledge that without God, this study would never have been possible. Thank you, Lord Jesus, for your goodness and mercy that follow me all the days of my life! This research, and subsequent film, has been several years in the making. The work has been long and taxing, but I devoted myself to finishing. Though the typography has been nothing short of mountainous, wrought with many unexpected twists and turns, it has also been rewarding. What a surprise it has been that this opportunity would grow my faith. I never would have made it without holding on to you, Lord.

To Brian, Elijah, and Bianca—thank you! I am so grateful you were there. You guys contributed greatly to my sense of sanity in the un-rosiest of circumstances. To Brian, my beautiful rock, thank you for supporting and cheering me on throughout this entire process. I know you delayed your own personal plans to instead stay by my side during the most difficult part of this process, all while feeding me the most delicious pot roasts and spaghetti dinners known to man. I will never forget your sacrifice. To Elijah and Bianca, you never knew this but your simple encouragements, “You got this, Granny!” came at perfect times when I was feeling low. What a blessing you both are!

Then, there is Kēnneth, who deserves his own paragraph. Kenn, you have endured the hardest stages of this experience with me, and continually showed heartfelt interest and real excitement for my research. Thank you for the phenomenal formatting and

beautiful charts—they really turned out amazing. I could not have done them without you. Thank you for your enduring support through the dredged sand. Your love and patience have made all the difference. This degree is truly *our* degree. Thank you, for you. Thank you, for everything.

*This is just the beginning for you.* Those were the inspiring words of my wonderful advisor and kindred spirit, Dr. Bernadette Marie Calafell. Thank you, Bernadette for seeing my vision for this project, and never giving up on it. Thank you for calling me an *artist* and a practitioner. You will never know how much those words mean to me. Thank you for looking at me with kindness, for the heads up, and for all the millions of things you did behind the scenes to support me.

A huge thank you goes to the late Dr. Roy Wood, whose intellectual generosity matched his collegial warmth. I was so very blessed to be encouraged by this great scholar and true gentleman. I also would like to express my sincere appreciation to Dr. Mary Claire Loftus, Dr. Christina Foust, and Dr. Santhosh Chandrashekar. I also thank Paula Martin Nobles. You are all so very brilliant and I marvel at your intelligence. Thank you, a thousand times, for your kindness, prayers, and support through this journey.

I owe an enormous debt of gratitude to the University of Denver, Department of Media, Film and Television Studies. When it comes to original perspective and inspiration, there is no other pillar of strength and sheer awesomeness quite like the extraordinary Dr. Sheila E. Schroeder. I was lucky enough to study under Dr. Schroeder, who introduced me to a totally different world—the world of filmmaking where I could

truly be myself. It was in her classroom where the lightbulb went off and I was first exposed to the possibility of creating a film for this study. Sheila, you are without a doubt, one of the most amazing and encouraging educators I have ever encountered. Thank you for reminding me to *keep my eye on the prize...* and for reminding me of the day when I would, *cross the finish line, chest out, breaking the tape.*

I must thank Sally, my dear friend and loyal supporter. Thank you for coming out to the freezing film location with me, our bones rattling like ice cubes in a glass, and yet, encouraging me every moment. You're the best! Thank you Deb, for being the very first person to call me, Dr. Wanda Lakota. Your voice saying those words always made me smile. You're awesome! Thank you Dana, for being an absolutely brilliant social scientist in the field of genealogy. Thank you for always being just a phone call away. I am so very grateful for the laughter and encouragement, and for the many hours sitting in restaurants talking about our projects. Thank you Ty and Vi for the many, many phone calls, your love, and your support. Vi, I will never forget the strength of your hand, *oh, my*, holding mine during that most difficult moment. Pastor Ty, I will never forget the Bible verses and reminders of the love of Jesus Christ, a love that shines through your very soul, and is infused in the uplifting words that roll off your spirit. Thank you, Ty and Vi, for walking with me during a most difficult walk.

This acknowledgement has only skimmed the surface, for each of these very special, extraordinary beings, in their own multi-faceted ways, are irreplaceable. We do not remind ourselves of that enough. I am so grateful for you all.